Thyroid Foundation of Canada
La fondation canadienne de la thyroïde

thyrobulletin 30th Anniversary Edition

October 2010

thyrobulletin

TFC's New Board of Directors

Front, left to right, Ashok Bhaseen- President, Mabel Miller- Vice President,
Back, left to right, Catherine Fey-Treasurer, Dagmar VanBeselaere- Director, John Hannigan- Director, Donna Miniely-Secretary

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Happy Birthday and Good Luck for the future. We wish you many good years to come!

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Fondatrice: Diana Meltzer Abramsky, C.M., B.A.

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Message from the President

I have been the President of TFC for two years. During this period, I have learned a great deal concerning running and managing a volunteer organization. If an organization is to succeed, it needs vision, direction and a team that can make things happen. However, in an organization such as ours, everything begins and ends with people and therefore people become the prime ingredients of any successful outcome. While managing TFC along with its Board of Directors, the following observations come to mind as essential components of a successful organization:

- Passion for voluntary service as there are no monetary gains
- Selfless actions, having an inherent desire to make a difference in someone's life
- Organizing self and family life to leave room to serve the organization
- Finding reason for the 'To Do's as there are plenty of 'Not to do'.
- Drive- and plenty of it
- Enthusiasm, compassion for others
- Teamwork and respect for other team members
- Ability to remain focused despite difficulties
- Making it happen and in a timely manner

In general, people who understand and embrace the above, make good volunteers and are successful in managing their respective positions. However, those who are in responsible positions must also be open to talk with passion about the organization with others and even complete strangers. They should be able to inspire others to become part of the organization. Managing at the helm or managing an organization activity takes dedication, time, effort as well as the ability to deal with a lot of issues. This is where a positive 'can do' attitude becomes a must. Most issues are opportunities and should be dealt with in that fashion. There will always be people in a team, with different ideas, strengths, attitudes and divergent thinking. The sum of these parts is what makes a strong and dynamic team.

However, when one or more members who sit on an organization's executive board try to garnish too much attention to their own self and worth, it derails the team's overall efforts. As a result, this becomes detrimental to the growth and success of the organization. This leads to a lot of time being invested in satisfying egos and resolving the sundry issues that arise between individuals who have to work together during team meetings and conference calls. The whole organization gets impacted with these conflicts.

As a result, strategic plans get eroded and there are delays in completing the tasks on hand. These issues primarily stem from individuals who have never before worked as part of a functional team and for others who do not have, as yet, the requisite skills needed for the position they serve. Quite often, organizations are not able to successfully cultivate a team of successors and succession planning does not take shape. This is where some volunteer organizations face closure and, sadly, the people who are impacted the most are the patients themselves who need it the most.

The question then becomes what did we achieve in these past 2 years?

Consider a summary of the following key accomplishments of our organization:

1. Financial health of the organization
2. New Website that will be equally accessible in both Official Languages
3. New updated Thyroid Health Guides
4. Revival of thyrobulletin
5. Renewal of strong relationships with TFI, Industry and the Endocrinology community
6. Renewed commitment of TFC members and chapters across Canada
7. Building the TFC office with access to bilingual services for its members and the general public

Thyroid Foundation is in its 30th Year of continuous service to Canada and it has been a beacon of light to other foundations across the globe. TFC has seen it ups and downs, and unfortunately, the downs had become detrimental to our growth as it takes five times the effort to get back on track. In response, our 30th Anniversary celebrations were a litmus test to our overall efforts and mission. Our vision at TFC to provide leadership to manage thyroid disease is still intact. Our goals of promoting awareness and education, lending moral support to patients and their families and raising funds for research remain the same.

When you think of it, 30 years of organizational history is hard to deny. Our history has structure, and a strong foundation. It possesses a collective memory, rules, regulations and an ever running pool and fountain of experience. At the same time, not everyone wants to lead and not everyone wants to be part of the day –to- day running of a national organization. Many want to support an organization that is dear to their issues and heart. We need these people, within our ranks, with their passion, drive and a commitment to the cause. The rest will come from experienced members of our organization who can nurture, encourage and motivate others to go beyond. Think of our organization as a seed that will blossom into flowers with the right amount of ingredients necessary for growth.

Since June 2008, TFC has had to work hard to recapture its vision and our commitment to patients. Fortunately, the serious commitment and dedicated service that some of our members have given to the organization in the last two years, has paid off and we now see a revitalized and viable TFC. When someone is able to give of one's time selflessly to someone else, it becomes a truly remarkable experience for that individual. Volunteer spirit comes from within and serving as a volunteer can make a significant difference in someone's life.

For this, we need to be thankful to the powers that be. These powers help us reach a stage in our life where we are willing and able to give some of our time to a good cause. I encourage our readers to share their volunteer experience with others who may be thinking of embarking on this amazing journey. It is a very satisfying experience, not in monetary terms but in making one's life richer by its very experience.

Ashok Bhaseen

Un message du Président de la FCT

Cela fait maintenant deux ans que je suis Président de la FCT. Au cours de cette période, j'ai beaucoup appris sur l'administration et la gestion d'une organisation bénévole. Afin qu'une organisation puisse réussir, il lui faut un but précis, une bonne gestion et une équipe prête à l'action. Cependant, dans une organisation comme la nôtre, tout commence et finit avec des gens. Les gens sont donc les ingrédients principaux de toute réussite. En administrant la FCT en association avec son comité de direction, nous observons les éléments essentiels suivants qui contribuent à la réussite d'une organisation :

- une passion pour le bénévolat : on n'y tire aucun profit financier;
- des actions pleines d'abnégations, avoir un désir inné de vouloir faire une différence dans la vie d'autrui;
- organiser sa vie privée et familiale afin d'allouer du temps pour servir l'organisation
- trouver toutes les bonnes raisons d'agir, puisqu'il y a tant de raisons qui incitent à ne rien faire;
- de la volonté – et ce, en abondance;
- de l'enthousiasme, de la compassion envers son prochain;
- le travail d'équipe et le respect des autres membres du groupe;
- la capacité de maintenir ses objectifs en dépit des difficultés qui peuvent surgir;
- agir dans un délai raisonnable.

En général, les gens qui comprennent et adoptent ce que nous venons d'énoncer ci-haut font d'excellent bénévoles et réussissent dans leurs tâches respectives. Cependant, ceux qui occupent une position en tant que responsable doivent également être en mesure de parler de l'organisation aux autres avec conviction, même aux inconnus. Ils devraient pouvoir inspirer les autres à se joindre à l'organisation. La gestion dans son ensemble, ou la gestion d'une organisation, requiert du dévouement, du temps, de l'effort, ainsi que la capacité de faire face à bon nombre d'obstacles. Une attitude positive et dynamique devient alors nécessaire. La plupart des problèmes sont des opportunités et devraient être résolus avec cette mentalité.
Au sein de toute équipe, il y aura toujours des gens avec des idées, des forces et attitudes différentes, ainsi que des gens ayant des idées divergentes. La somme de ces parties est à la base d'une équipe forte et dynamique. Cependant, si un ou plusieurs membres du comité de direction a tendance à trop fixer l'attention sur lui-même et ses propres mérites, ceci porte atteinte aux efforts collectifs de l'équipe. Ceci peut nuire à la croissance et à la réussite de l'organisation. Beaucoup de temps est gaspillé à satisfaire l'égo des uns, et à résoudre divers problèmes entre les mêmes individus qui devraient travailler ensemble lors des rencontres d'équipe et des conférences téléphoniques.

L'organisation dans son ensemble est affectée lors de ces conflits. Ce qui suit est une perturbation des plans stratégiques et des retards dans la progression des tâches à compléter. Ces situations proviennent surtout d'individus n'ayant jamais fait partie d'une équipe fonctionnelle, ou de ceux qui n'ont pas encore les compétences requises pour le poste qui leur est assigné. Certaines organisations sont très souvent incapables de cultiver une équipe de successeurs, et souvent il n'y a aucune planification en matière de succession. Voilà donc les raisons pour lesquelles certaines organisations bénévoles font face à une fermeture et, malheureusement, les personnes les plus affectées sont celles qui sont réellement dans le besoin : les patients.

La question est celle qui suit : Qu'avons nous accompli au cours des deux dernières années? Considérons donc un aperçu des accomplissements majeurs de notre organisation :

1. la solidité financière de l'organisation;
2. le nouveau site web qui sera accessible dans les deux langues officielles;
3. de nouveaux Guides de la santé thyroïdienne mis à jour;
4. une reviviscence du Thyrobulletin;
5. un renouvellement des liens solides avec la TFI, l'industrie et la communauté d'endocrinologie;
6. un renouveau de la dévotion des membres de la FCT et des sections régionales à travers le Canada;
7. la construction du bureau de la FCT qui rendra accessible des services bilingues aux membres et au public.

La Fondation de la thyroïde est au service du Canada depuis maintenant 30 ans et sert d'exemple aux autres fondations à travers le monde. La FCT a connu ses hauts et ses bas, et malheureusement, les moments de faiblesse ont ralenti notre croissance et il nous faut cinq fois plus d'efforts pour reprendre le dessus. Nos célébrations du 30ème Anniversaire furent une épreuve décisive pour nos efforts et notre mission. La vision de la FCT, celle d'être chef de file dans l'aide à la gestion de la maladie thyroïdienne, demeure intacte. Notre objectif, qui consiste à sensibiliser et à éduquer, à donner un support moral aux patients et à leurs familles et à lever des fonds pour la recherche, reste inchangé.

Quand on y songe, il est difficile d'oublier 30 ans d'histoire organisationnelle. Notre histoire est structurée et ses fondements solides. Elle possède une mémoire collective, des règlements et une source intarissable d'expérience. Malgré tout, ce n'est pas tout le monde qui souhaite diriger ou prendre part dans les activités quotidiennes d'une organisation nationale. Beaucoup sont ceux qui souhaitent appuyer une organisation qu'ils tiennent à cœur. Nous avons besoin que ces gens fassent partie de nos rangs, qu'ils partagent avec nous leur passion, leur volonté et leur dévouement à notre cause. Le reste viendra des membres expérimentés qui sauront encourager, encadrer et motiver les autres à aller de l'avant. Pensez à notre organisation comme étant une graine qui grandira et qui portera fruit si on lui donne les éléments nécessaires à sa croissance.

Depuis juin 2008, la FCT a dut travailler dur pour reprendre sa vision et son dévouement aux patients. Heureusement, le dévouement sérieux et le service dédié que certains de nos membres ont su offrir à l'organisation au cours des deux dernières années ont porté fruit, et nous avons maintenant une FCT viable et ravivée. Lorsqu'on est capable de donner son temps à autrui de façon désintéressée, cela devient réellement une expérience tout à fait remarquable. L'esprit du bénévolat vient au fond de soi et peut faire toute la différence dans la vie de quelqu'un. Pour ceci, nous devons être reconnaissants envers la puissance supérieure. Cette puissance nous aide à atteindre une étape de notre vie où nous sommes disposés et capables de donner une part de notre temps pour une juste cause.

J'encourage nos lecteurs à partager leur expérience de bénévolat avec ceux qui songent peut-être à emprunter ce parcours remarquable. C'est une expérience très satisfaisante qui n'est peut-être pas lucrative financièrement, mais qui offre l'opportunité d'enrichir sa propre vie en jouissant d'une telle expérience.

Ashok Bhaseen

Thyroid Foundation of Canada 30th Anniversary June 4-6th, 2010

Thyroid Foundation of Canada held its 30th anniversary in its capital city of Ottawa. The festivities were spread over 3 days from June 4th to June 6th, 2010. TFC members and executives were represented from Atlantic Canada, i.e. Newfoundland to Victoria, BC on the pacific coast of Canada. France and Australia were also represented at this landmark occasion in the history of TFC. This was a proud moment for TFC and its members; an organization that was initially formed in Canada and continued to spread its message and vision around the globe. The goal of our landmark celebration was to ensure that TFC is a revitalized and up-to-date organization. We encouraged each other to bring our members and current developments up to date so that together, we can leverage the latest developments in the field of thyroid research. In this way, patients can bring their life back to normal. A landmark celebration of this kind takes a year of work, dedication of its core team and members to ensure a smooth execution. When an organization commits itself to such a celebration, it rallies its members to carry out the many objectives and plans being implemented by its teams all across the nation. The same can be said about the TFCs 30th anniversary where all members chipped in to make this a landmark occasion.

Day one i.e. June 4th , 2010 started with a reception that was attended by many past executives and members who played an important role for over 20 years in many cases and some as much as 30 years of dedicated service to the TFC. The years have not dampened the spirits but only reinforced a strong commitment to the continued growth of the organization. Many of the committed Endocrinologists who care for the thyroid disease and who were also chosen as speakers for the 30th anniversary graced the occasion. Two TFC members who are very talented in their field i.e. Tracy K from Thunder Bay, Ontario, Canada and Donna Lynn Larson from Vancouver, BC, Canada kept the audience glued to their chairs during an entertaining and educational evening with their blues and one-act play respectively. To mark this historic occasion, one full day was dedicated to continuing education on thyroid issues with a mosaic of patients facing different issues.

The following topics were presented to the patients and physicians who attended the program:

1. Unresolved Issues in the Management of Hypothyroidism*: Dr Gerald JM Tevaarwerk,* Victoria, BC, Canada
1. To review new evidence about peripheral thyroid hormone metabolism and its regulation.
2. To review the adequacy of the current paradigm for the treatment of hypothyroidism.
3. To review the clinical utility of TSH as the biochemical indicant of euthyroidism

2. Hyperthyroidism: *Dr Hortensia Mircescu,* U of Montreal, Canada
1. Attain an understanding of the manifestations of hyperthyroidism
2. Formulate an investigation and treatment algorithm in hyperthyroid patients
3. Acquire knowledge about the side effects of treatment modalities in hyperthyroidism

3. Thyroid Eye Disease, Speaker: *Dr Jack Wall,* Sydney, Australia
1. Assess and classify the signs of the eye disease associated with Graves hyperthyroidism & Hashimoto's thyroiditis
2. To understand the role of orbital and thyroid imaging and blood tests in the diagnosis and management of TED.
3. To have an understanding about the possible mechanisms for the link between ophthalmopathy and thyroid disease

4. Thyroid cancer: *Dr Hortensia Mircescu,* U of Montreal, Canada
1. Describe the risk factors for malignancy in a thyroid nodule
2. Attain an understanding of the current treatments of well differentiated thyroid cancer

3. Acquire understanding of clinical, biological and imaging tools used for the long-term follow-up of thyroid cancer patients

5. Thyroid Surgery: *Dr Richard Payne, McGill University,* Montreal, QC, Canada
1. Attain an understanding of the current indications for thyroid surgery
2. Acquire basic knowledge about thyroid surgery complications and their management

6. Pediatric aspects of thyroid disease: *Dr Guy Van Vliet,* U of Montreal, QC
1. Achievements and limitations of the neonatal screening program for thyroid problems
2. Impact of thyroid diseases on the health of children and adolescents
3. Diagnostic and treatment procedures used for thyroid disease in paediatrics

7. Thyroid disease and pregnancy: *Dr Wendy Rosenthall*, Toronto, ON
1. Acquire an understanding of normal changes in thyroid function associated with pregnancy
2. Comprehend the impact of hyperthyroid states and pregnancy and their management
3. Understand the interrelation between hypothyroid states and pregnancy

Dr. Hortensia Mircescu was awarded a plaque for her efforts in revitalizing, 12 Thyroid Guides in English and French. Drs Rosenthall, Payne, Guy Van Vliet and Gerald JM Tevaarwerk were recognised for their commitment and dedication to TFC and its patient needs.

The education day was supported by a number of displays that were put up by Chapters, Industry and TFC volunteers. The occasion was marked by TFC 30th Anniversary memorabilia, key chains with medal head engraved with 30th Anniversary and TFC logo, Fridge magnets with 30th Anniversary and TFC logo, T-Shirts with a specially-designed 30th Anniversary pattern created by Catherine Fey. Specially embroidered Golf Shirts could also be custom-ordered by members and attendees. It was great to see young volunteers with thyroid issues giving sincere helping hands to the efforts of TFC. The education day was followed by a tribute evening to salute the volunteer efforts of different chapters and individuals who have made a significant contribution to TFC. Kingston, London, Kitchener-Waterloo, Gander, Toronto and Ottawa chapters were recognized with their accomplishments. Dr Jack Wall, who travelled from Sydney, Australia, was recognized as the 'Star of TFC' and a special award was presented to him to recognize his efforts to TFC spanning three decades.

Mabel Miller (for her dedicated service to Gander Chapter and TFC National for 15 years), Dagmar Van Beselaere (for her dedicated service to the Ottawa Chapter and her contribution to the 30th Anniversary celebration), Catherine Fey (voluntary services for the 30th Anniversary), Phillip Morrissey (for excellent legal

guidance and support to TFC), Barbara Cobbe (for her dedicated services to the London Chapter and TFC National), Marjorie Miniely (for her decades of dedicated service to TFC), Ashok Bhaseen for his leadership to TFC during tough times and Keith Barklem, TFC Treasurer who has played an important role in getting all the financial history of TFC together since 2004.

Beate Bartès from France represented the TFI. She read a message from the TFI president Yvonne Andersson. She also commenced the session on Thyroid Cancer that was dedicated to her efforts on the subject. She shared her efforts being undertaken in France and also updated the audience on TFI efforts.

The third and final day was dedicated to a keynote speech given by Dr Jack Wall. Dr. Wall inspired our members by encouraging them to continue their efforts within TFC. He stated that an organization like TFC plays an important role in generating awareness, helps other patients and invests in key research findings that can benefit the patients. This was followed up by a presentation by Ashok Bhaseen, President of TFC. Mr. Bhaseen shared the vision, mission and objectives of TFC and presented a strategic plan. The key objectives do not change but remain focused on generating funds for research in Thyroid Disease, Thyroid Awareness and providing all the necessary tools to patients suffering from thyroid issues.

There was a renewed pledge from the members to make things happen, as TFC has come a long way and needs to continue to revitalize it to be a viable organization that can make a difference to the patients. Both Joan DeVille (Kitchener-Waterloo) and Mary Salsbury (Kingston) provided an insight into their efforts and shared it with the members during the AGM. Cassandra Howarth (Kitchener-Waterloo) also played an old CD of a past TFC meeting that brought back memories to some TFC members

During the AGM a new team was elected to replace the ones retiring and now the board has following members:

Ashok Bhaseen- President
Mabel Miller-Vice President
Donna Miniely-Secretary
Dagmar Van Beselaere-Director
John Hannigan-Director
Catherine Fey-Treasurer

The 30th Anniversary truly helped in renewal of faith and dedication in the organization both from the patients' and the Physicians' side. There is a firm commitment to generate funds to some very needed projects in the thyroid disease.

30ème Anniversaire de la Fondation canadienne de la thyroïde 4 au 6 juin 2010

La Fondation canadienne de la thyroïde (FCT) a célébré son 30ème anniversaire à Ottawa, la capitale nationale du Canada. Les festivités ont eu lieu du 4 au 6 juin 2010. Des membres et dirigeants de la FCT provenant du Canada, de l'est de l'Atlantique (Terre-Neuve) aux côtes du Pacifique (Victoria, Colombie Britannique), ainsi que des représentants de la France et de l'Australie, étaient de la partie pour célébrer cet événement marquant dans l'histoire de la FCT. Ce fut tout un moment de fierté pour la FCT et ses membres. La FCT est une organisation qui a pris naissance au Canada et qui communique son message et sa vision à travers le monde entier. Le but de notre grande célébration était d'assurer que la FCT soit une organisation ravivée et moderne. Nous nous sommes encouragés les uns les autres à actualiser nos projets et à garder nos membres informés pour que nous puissions ensemble comprendre les nouvelles découvertes dans le domaine de la recherche sur la thyroïde. De cette façon, la vie des patients pourra revenir à la normale. Une telle célébration prend un an de travail et le dévouement du conseil exécutif et de ses membres afin d'assurer une exécution sans faille. Lorsqu'une organisation se dédie à une telle célébration, cela inspire ses membres à s'unir afin d'atteindre les nombreux objectifs fixés par les équipes à travers le pays. On peut en dire de même à propos du 30ème anniversaire de la FCT où les membres se sont tous unis pour faire de cet événement un véritable succès.

La première journée, qui eut lieu le 4 juin 2010, débuta avec une réception à laquelle ont assisté plusieurs anciens membres et les membres actuels qui ont joué un rôle important au sein de la FCT au cours des vingt à trente dernières années. Le passage des années n'a certainement pas affaibli les esprits mais, en revanche, a servi à renforcer le dévouement des membres et la croissance de l'organisation. Plusieurs endocrinologues, pour qui la maladie thyroïdienne est une grande préoccupation, ont su nous accorder leur présence et ont été choisis comme orateurs. Deux membres de la FCT experts en leur domaine, soit Tracy K. de Thunder Bay, Ontario, et Donna Lynn Larson de Vancouver, Colombie Britannique, ont su captiver l'attention des invités avec leur art au cours de cette soirée éducative et divertissante. Pour marquer cette occasion historique, une journée entière fut consacrée à la formation continue sur les problèmes reliés à la thyroïde grâce à des patients faisant face à divers troubles thyroïdiens.

Les sujets suivants furent présentés aux patients et aux médecins qui étaient présents lors du programme

1. Questions non résolues dans la gestion de l'hypothyroïdie : *Dr Gerald J.M.Tevaarwerk,* Victoria, Colombie Britannique, Canada

1. réexaminer les nouvelles découvertes sur le métabolisme périphérique des hormones thyroïdiennes et sa régulation
2. réexaminer la pertinence du paradigme actuel dans le traitement de l'hypothyroïdie
3. réexaminer l'utilité clinique de la TSH comme indicateur biologique de l'euthyroïdie

2. *L'hyperthyroïdie* : *Dre Hortensia Mircescu,* Université de Montréal, Montréal, Québec, Canada

1. arriver à connaître les manifestations de l'hyperthyroïdie
2. formuler une enquête et un algorithme de traitement pour les patients hyperthyroïdiens
3. acquérir une connaissance des effets secondaires *des modalités de traitement pour l'hyperthyroïdie*

3. *L'Ohphtalmopathie thyroïdienne*: *Dr Jack Wall,* Sydney, Australie

1. évaluer et classer les signes de la maladie de l'œil associée à l'hyperthyroïdie de Graves et la thyroïdite d'Hashimoto

2. comprendre le rôle de l'imagerie orbitaire et thyroïdienne, ainsi que les examens sanguins dans le diagnostic et la gestion de l'ophtalmopathie thyroïdienne
3. comprendre les mécanismes potentiels du lien entre *l'ophtalmopathie et la maladie thyroïdienne*.

4. *Le cancer de la thyroïde* : *Dre Hortensia Mircescu,* Université de Montréal, Montréal, Québec, Canada
   1. décrire les risques de malignité dans un nodule thyroïdien
   2. prendre connaissance des traitements actuels pour le cancer bien différencié de la thyroïde
   3. acquérir une connaissance des outils cliniques et biologiques, ainsi que des outils d'imagerie utilisés pour le suivi à long terme des patients atteints d'un cancer thyroïdien

5. *Chirurgie thyroïdienne* : *Dr Richard Payne,* Université McGill**,** Montréal, Québec, Canada
   1. comprendre les indications actuelles pour la chirurgie thyroïdienne
   2. acquérir une connaissance de base des complications d'une chirurgie thyroïdienne et la gestion desdites complications

6. *Aspects pédiatriques de la maladie thyroïdienne* : Dr Guy Van Vliet, Université de Montréal, Montréal, Québec, Canada
   1. progrès et limitations du programme de dépistage des problèmes thyroïdiens néonatals
   2. impact de la maladie thyroïdienne sur la santé des enfants et des adolescents
   3. procédures de diagnostique *et de traitement utilisés en pédiatrie pour la maladie thyroïdienne*

7. *La maladie thyroïdienne et la grossesse* : *Dr Wendy Rosenthall*, Toronto, Ontario, Canada
   1. comprendre les changements normaux de la fonction thyroïdienne associés à la grossesse
   2. comprendre l'impact des états hyperthyroïdiens sur la grossesse et la gestion de ces états
   3. comprendre la relation entre les états hypothyroïdiens et la grossesse

Une plaque fut offerte en guise de remerciement au Dre Hortensia Mircescu pour ses efforts investis dans la mise à jour des 12 Guides de la thyroïde, offerts en français et en anglais. Les docteurs Rosenthall, Payne, Van Vliet et Tevaarwerk furent reconnus pour leur engagement et dévouement envers la FCT et envers les besoins de leurs patients.

La journée éducative fut possible grâce à des affiches érigées par des bénévoles de nos chapitres, de l'industrie et de la FCT. L'occasion fut marquée par des souvenirs portant le logo du 30ème anniversaire de la FCT, tels que des porte-clés et des aimants de réfrigérateur, ainsi que des chandails portant un motif spécial du 30ème efforts de la FCT. Les sections régionales de Kingston, Kitchener-Waterloo, Gander, Toronto et Ottawa, furent reconnus pour leur contribution. Dr Jack Wall, qui est venu de Sydney, en Australie, fut reconnu comme « l'Étoile de la FCT » et un prix lui fut décerné pour ses efforts continus au sein de la FCT depuis les 30 dernières années. Les personnes suivantes reçurent également un prix pour leurs contribution: Mabel Miller pour ses services au sein de la section régionale de Gander et de la FCT Nationale depuis 15 ans ; Dagmar pour ses efforts au sein de la section régionale d'Ottawa et pour sa contribution aux célébrations du 30ème anniversaire ; Catherine Fey pour son bénévolat lors des célébrations du 30ème anniversaire ; Phillip Morrissey pour ses excellents conseils juridiques et son appui ; Barbara Cobbe pour ses services au sein de la section régionale de London et de la FCT nationale ; Marjorie Miniely pour ses nombreuses années de service avec la FCT ; Ashok Bhaseen pour son leadership lors des temps difficiles de la FCT ; Keith Barklem, trésorier de la FCT qui a su gérer les finances de la FCT depuis 2004.

Beate Bartès, venue de France, représentait la TFI. Elle lut un message de la présidente de la TFI, Yvonne Andersson. Elle débuta également une session sur le cancer de la

thyroïde qui discutait de ses efforts envers la cause. Elle discuta de son travail en France et en profita pour faire connaître les progrès de la TFI.
La troisième et dernière journée fut consacrée à un discours par le Dr Jack Wall. Dr Wall inspira nos membres en les encourageant de continuer leurs efforts au sein de la FCT. Il fit remarquer qu'une organisation comme la FCT joue un rôle important au niveau de la sensibilisation des gens, aide les patients et investit dans d'importantes recherches qui peuvent venir en aide aux patients. Ceci fut suivi d'une présentation par Ashok Bhaseen, Président de la FCT.

M. Bhaseen partagea la vision, la mission et les objectifs de la FCT, ainsi qu'un plan stratégique. Les objectifs principaux demeurent inchangés et restent toujours fixés sur la levée de fonds pour la recherche dans le domaine de la maladie thyroïdienne, sensibiliser le public et offrir tous les outils nécessaires pour venir en aide aux personnes souffrant de troubles thyroïdiens. Les membres ont renouvelé leur engagement à toujours demeurer actifs pour ainsi permettre à la FCT de demeurer une organisation qui puisse toujours faire une différence dans la vie des patients. Joan DeVille (Kitchener-Waterloo) et Mary Salsbury (Kingston) ont discuté de leurs efforts avec les membres au cours de l'assemblée des actionnaires AGM. Cassandra Howarth (Kitchener-Waterloo) eut l'idée de faire entendre un CD d'une ancienne rencontre, ce qui ramena beaucoup de souvenirs à certains membres de la FCT.

Au cours de l'AGM, une nouvelle équipe fut élue afin de remplacer les membres qui ont pris leur retraite. Le comité est maintenant composé des membres suivants :

Ashok Bhaseen- Président

Mabel Miller- Vice-président

Donna Miniely- Secrétaire

Dagmar VanBeselaere- Directeur

John Hannigan- Directeur

Catherine Fey- Trésorière

Le 30ème anniversaire a réellement contribué à renouveler la fidélité et le dévouement au sein de l'organisation, autant du coté des patients comme de celui des médecins. Nous sommes voués à générer les fonds nécessaires pour d'importants projets dans la lutte contre la maladie thyroïdienne.

Message from Mabel Miller, Vice-President

It's with much pleasure that I offer congratulations and good wishes to Thyroid Foundation of Canada on the occasion of The 30th Anniversary. The Thyroid Foundation of Canada has been a wonderful experience for me. In 1990 I saw an article in our local newspaper about an information session to be held on thyroid disease. Having been diagnosed with thyroid disease some years previous I was curious. I then made up my mind to find out about my condition as it was still a mystery to me. However, on that particular date of the information session, I had to go out of town on business and could not be there. Thankfully, my husband volunteered to check this out for me. I had no idea there were others around me that had thyroid disease or really what thyroid disease was all about. The information session led to me being appointed as part of a steering committee and as they say "the rest is history" .

The Gander Area chapter was formed in 1990 where I spent some time as President and then went on to become involved on the National Board on several occasions.

TFC has given me better understanding of what thyroid disease is all about. I have benefited much along with others being part of an organization where I could find out more about what was happening to my body as well as to provide awareness to others.

As well, along the way I have met many wonderful people who through TFC have become great friends and acquaintances. It is my wish that TFC will continue well into the future providing education, promoting awareness and much needed research on thyroid disease. I look forward to many others becoming involved and assisting in this organization to grow to its fullest potential. Remember, it's your health or the health of someone close to you too that will benefit.

Mabel Miller, Vice President
National Board
Thyroid Foundation of Canada

Ottawa, 30th Anniversary of TFC

Dear Ashok, President TFC, dear members of Thyroid Foundation of Canada,

Thyroid Federation International, in short TFI, is an umbrella organization and a network for thyroid patient organizations worldwide. It was founded in 1995 by Diana Abramsky who wanted to bring the important thyroid questions to an international level. This was the important first step for thyroid patients all over the world. Today, 15 years later, member organizations exist in five of the six continents. TFI provides evidence- based information; helps start new patient groups, follows the research within the thyroid area and works in good co-operation with medical thyroid specialists for the mutual benefit of both the patients and doctors.

In the 15 years that the TFI exists, TFC has been the mother organization for TFI activities. Next to Diana Abramsky, the names of Robert Volpé, Arlis Beardmore and June Rose-Beatty come up. Next to many names I forget, I especially want to mention Katherine Keen, who has been working for TFI since I don't know how long, next to her work for TFC. And now, after she left TFC, she still is taking care of the administration for TFI.

We want to thank Mr. Ashok Bhaseen, for his invitation for this 30th anniversary of the oldest thyroid patient organization in the world. Therefore, we are glad, happy and very proud to congratulate Thyroid Foundation of Canada, our mother organization, to the 30 years of existence and the great work that has been put into the Foundation. The last couple of years have been tough for TFC - but you made it, which is a proof of what good will can achieve.

We wish you many good years to come!

We also wish for a long lasting relation between Thyroid Foundation of Canada and Thyroid Federation International – thyroid patients worldwide!

Happy Birthday and Good Luck for the future.

Yvonne Andersson, President of TFI

Thyroid Memories

The Thyroid Foundation of Canada has accomplished a great deal over the last thirty years and I have been proud and honoured to be a part of it. It was a tremendous amount of support to me when I was really sick. Being a volunteer for the Foundation has once again proven to me that anything you do comes back to you tenfold.

I have been a thyroid patient since 1975 when at the age of fourteen, I had my first thyroid operation to remove a cyst on the outside of my thyroid. I was in grade ten at the time and I clearly remember my friends coming to visit me at the local hospital and afterwards being called, "Frankenstein's girlfriend" because of the visible scar across my neck. The first operation and experience was not too bad. I don't remember feeling sick and feeling any pressure when I had the "lump" in my neck. My second experience as a thyroid patient was in 1981 when I was first married and had just finished my second year of university. This time the lump was quite pronounced and pushed on my trachea. I was very uncomfortable and understandably so when I found out it was the size of "golf ball." It took some time for me to convince the doctor that the lump was actually there because I was told at the time it was "marriage jitters." Anyway,

I had my second operation in 1982 eight years after my first operation. My third and hopefully final experience with my thyroid was during my second pregnancy. This time I really didn't feel well. I couldn't breathe and my heart was palpitating. The third and final operation occurred after two years of convincing doctors there was really something wrong with me. I had "hyperthyroidism" and was put on "propylthiourcil" while I was still pregnant. I had over twenty nodules in my thyroid which was "half of my thyroid gland." I had the right side removed with my second operation. I really didn't get much better and felt awful all of the time. I switched doctors and was offered "radio-active iodine" as a treatment. I simply could not understand how that would help with my nodules which were definitely pushing my trachea sideways. You could even see it on the x-rays. I insisted on an operation. After that I began a long journey of trying to get the right dose of thyroxine. With the help of my Mother, I eventually started taking a combined dose and woke up one day with all symptoms of "hyperthyroidism" and "hypothyroidism" completely gone. I eventually learned from Dr. Volpé that I had Grave's disease along with all of the nodules. No other doctor had ever mentioned that to me.

My third operation was exactly eight years from the second operation. During the time that I was trying to convince all of the doctors to let me have an operation, my mother-in-law saw an advertisement in a Toronto newspaper for a public education meeting of the "Thyroid Foundation of Canada." It was at Sunnybrook hospital. My parents and I drove down to Toronto to attend the meeting to see what it was all about. The year was 1990. I had never heard of the Thyroid Foundation of Canada. The meeting was very informative and I was thrilled to get more information about the thyroid. I think it was in the spring of 1990 just before my third thyroid operation. At the time I was drinking water with drops of iodine in it to prepare for my operation. What a horrible taste and imagine my horror when I picked up the bottle at the pharmacy and it was labelled "poison." I have to admit though I looked forward to it every day because it made me feel so much better.

In the summer of 1990, my mother saw an ad in the Kitchener-Waterloo Record and she called me. She said there was a Kitchener-Waterloo Area Chapter of the Thyroid Foundation of Canada and they were looking for volunteers. They had the position of "Secretary" and "Vice-President." I immediately called the phone number and volunteered for the "Vice-President" position. Margaret Evans, the Founder of the Chapter and the one person who answered the help line 24 hours a day, answered the phone. I told her that I was interested in volunteering for the "Vice-President" position and she said that she would appreciate it if I could take the job of "Secretary." She said the Vice-President really didn't do much and the chapter really needed a Secretary. I reluctantly agreed telling her I didn't think I would be much good at taking minutes. She thanked me profusely and so began my twenty year involvement with the Chapter. My next position was Education Chairman which was the perfect fit. I continued to learn and learn and learn at each meeting and each AGM and with each book. I read everything over and over again. I called the one book my "Thyroid Bible." A few years after becoming involved, we started having trouble finding volunteers. Margaret asked me if I would be the Education Chairman and the Vice-President. Don't worry she said, the Vice-President is just a figurehead unless something happens to the President. Well wouldn't you know it? The President decided to up and leave and I suddenly had two hats to wear. I eventually found another Education Chairman and stayed on as President. The same position I hold today. If you ask me, I will tell you. I was meant to be the Education Chairman and I continue to share my information to this day. I believe it's everyone's job to share what they know. Knowledge is definitely power and we need to make informed decisions.

Over the years, I have met many people involved in the Thyroid Foundation from across Canada as I attended many AGM's. The last few years have been hard and it's been a struggle to find volunteers. Everyone has such busy lives. Our Kitchener-Waterloo Chapter is still alive because there are still people who care. My family and their friends along with a few volunteers who have given many years of service are keeping our chapter alive. My mother, Joan DeVille is always the optimist. "We will run as long as the money lasts" she says when I would tell her it's no use. Things just aren't like they used to be. My sister-in-law, Tracey DeVille is the Secretary, my father, Derek DeVille Sr. is the Assistant Education Chairman, my niece, Danielle DeVille is the Vice-President and my husband, Colin Howarth is the Media Chairman. We still have Sandi Hebert, the Membership Chairman, who was recruited by my Mother because she worked with her. Sandi was also a friend of hers. Fatima Vitorino, Social Chairman and Helen Goldsworthy, Education Chairman have been with the chapter for many years. Dr. Margaret Evans, the Founder of the Kitchener-Waterloo Chapter, single-handedly answered the Kitchener Helpline from 1982 until 2009. Being part of the Foundation, as a member and a volunteer has allowed me to learn so much about Thyroid Disease. I can't imagine being any other place and as I sit writing this, it brings fear to my heart. Our most important goal has always been Education but we have learned that without fundraising we will be unable to meet that goal. I truly fear a future where I will no longer have access to the most current information on Thyroid disease. I truly hope that I never have to see a future without the Thyroid Foundation of Canada.

Cassandra Howarth

Our Memories of the Thyroid Foundation of Canada

Congratulations on the 30th Anniversary celebration. Our Chapter, the Kitchener-Waterloo, has been serving thyroid patients in our area since November 9, 1982. Thank you to dedicated people such as the Founder of Chapter, Dr. Margaret Evans, and others who gathered around Margaret's dining room table because they wanted to support others who were experiencing the same problems. John and Helen Goldsworthy, Fatima Vitorino are all very much involved to our Chapter in the past 27 years. Margaret has recently been honoured for all of her dedication by receiving the Ontario Senior Achievement Award from Queen's Park. She also received the Canada 125 Medal for founding the Chapter.

Derek and I became involved because of our daughter, Cassandra Howarth, who agreed to be the Secretary in 1991. I am the present Program Chairman and Derek is the Assistant Education Chairman. I have also served on the National Board for several years in the capacity of Chapter Development Chairman and Secretary. We still feel that helping those suffering from various types of thyroid disease has been very rewarding and a very important service to our community. We have also been fortunate to have the assistance of other family members as well as friends.

Joan and Derek De Ville, Kitchener-Waterloo Chapter

Let the TFC 30th Anniversary Celebrations Begin!

Dr Wendy Rosenthall and Dr Guy Van Vlient in discussion during June 5th, 2010 on TFC 30th Anniversary evening

June and Beate, meeting of friends after a long time

Dr Gerald JM Tevaarwerk presenting Donna Lynne Larson with certificate of appreciation for her one act play on Thyroid disease

Dr Richard Payne giving a lecture in the Ottawa Hospital Auditorium on the 30th Anniversary of TFC on June 5th, 2010

9th London Fashion Show

Dr Guy Van Vliet, from Montreal receiving certificate of appreciation from Sandy Hudgin on his talk for the 30th Anniversary

Dr Jack Wall, Sydney, Australia, recipient of "STAR of TFC" Award given for the 1st Time for 30 Years of Service and research work

Dr Hortensia Mircescu, TFC Medical Director, receiving certificate of appreciation from Marjorie Miniely on her talk for the 30th Anniversary

Ashok Bhaseen TFC President presenting Excellent Service award to Dr Hortensia Mircescu, Medical Director TFC

Beate Bartès from France-Forum Thyroid, addressing the audience on the 30th Anniversary of TFC on June 5th, 2010

Tracy K from Thunder Bay, on performing on stage on June 5th, Ottawa on the 30th Anniversary of TFC

Catherine Fey at the reception table at the 30th Anniversary of TFC on June 5th, 2010

Audience engrossed in 30th Anniversary program at Ottawa, June 5th, 2010

Dr Jack Wall, Dr Wendy Rosenthal and Dr Guy Van Vliet during a break, June 5th, 2010, at Ottawa

Megan and Didi,TFC co-ordinators with Ashok Bhaseen President of TFC on June 5th, 2010

From left to right, Dan Fey, Phillip Morrissey, Director Legal Affairs, Mabel Miller- Ashok Bhaseen, Catherine Fey at meeting held in London, Ontario on July 17, 2010

From the Archives: 30 Years Ago; An Event in Time of Historical Proportion for the TFC

Minutes of the initial meeting, June 24, 1980
Recorder by Mary Salsbury, Acting Secretary

What was hoped would he an historic event took place on June 24, 1980 when a group of some sixty people met in the Louise D. Acton building on George Street in Kingston, Ontario to discuss the formation of a Thyroid Organization.

Mr.Wally Viner assumed the role of Chairman and gave a short resume of the events leading up to this evening's meeting. The idea of the formation of a Thyroid Organization was the brainchild of an energetic lady, herself the victim of thyroid disease, Mrs. Diana Abramsky.

Mrs. Abramsky began her own research into thyroid disease when she first became ill and very quickly recognized the need, from the patient's point of view, for a better understanding of dysfunctions of the thyroid gland and the complications which sometimes result - in her case, complications of the eyes. In the course of her treatment she came under the care of Dr. Jack R. Wall, an Endocrinologist and Associate Professor of Medicine at Queen's University.

Dr. Wall is not only a physician engaged in the treatment of thyroid patients, but is also engaged in an active research program pertaining to the thyroid. Through her contact with Dr. Wall, Mrs. Abramsky became aware of the need for research and decided to see what she could do to raise funds - particularly in the field of thyroid eye research - and set for herself a goal of $l5,000.

With the help of Dr. Laurence Wilson, Professor and Head of the department of medicine, a fund has been set up at Queen's to which contributions can be made for this specific purpose. Those wishing to contribute were directed to send their contributions to the attention of Dr. Wilson. Queen's University denoting that they are for the Thyroid Eye Research Fund. Official receipts will be issued for tax purposes. The funds will be used locally by Dr. Wall. However, in addition to the need for research - and funds to carry it out, Mrs.Abramsky felt strongly another need existed - the need for an organization that could help to publicize the existence of this common disorder which may go undetected.

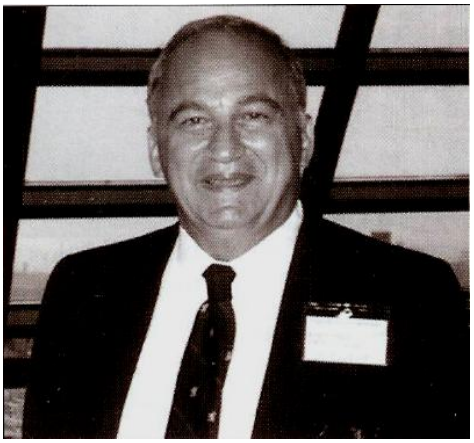
Such an organization could function in an educational way both for patients and their families and, ultimately, might become a national organization similar to the Cancer Society or the Heart Fund. The result of her efforts had, thus. culminated in this meeting. Against this background Mr. Viner then introduced Dr.Wall who gave an interesting and informative talk on the disorders of the thyroid.

This was followed by a lengthy question and answer period. There seemed little doubt that great benefit could be gained from an organization to which patients and their families could turn for help and information. and since no evidence can be found that there now exists a thyroid organization in Canada, it was agreed by those present that a small steering committee would be formed to meet in the near future to discuss the structuring of the organization.

A small group indicated their willingness to act. Mrs. Abramsky thanked those people who had come to the meeting as well as the many people in the community and the news media who had assisted her over the past few weeks.

The meeting adjourned at l0:l5 pm with the next meeting of the Steering Committee to be at the call of the Chairman.

From the Archives: A tribute to Dr Bob Volpé



Born and raised in, Toronto, Dr. Bob Volpé spent his entire life working to better the lives of thyroid patients worldwide. He was an endocrinologist, educator and researcher. He contributed to the Thyroid Foundation of Canada, served as a medical advisor of the Thyroid Federation International and was affiliated with the American Thyroid Association. He was educated at the University of Toronto and graduated in 1950 as an MD. He was a Fellow in Endocrinology at the University of Toronto from 1952 -53 and was NRC Fellow from 1955 - 57, He was appointed senior research fellow in 1957 and held that position until 1962 at which time Dr, Bob joined the faculty at the University of Toronto. Bob remained on faculty until his retirement from active teaching in 1992 and was named Professor Emeritus. He served on the medical staffs of several hospitals in the Toronto area - St. Joseph's Hospital, St. Michael's Hospital and Wellesley Hospital. Bob presented many guest lectures over the course of his career. He was the Hashimoto Memorial Lecturer at Kyushu University in Fukuoka, Japan in 1992. He was named K.J. R. Wightman Visiting Professor by the Royal College of Physicians in Canada in 1994 and presented the celebratory lecture commemorating the 200th anniversary of the birth of Robert Graves in Dublin, Ireland in 1996.

Bob was a staunch and loyal Canadian. He was instrumental in establishing the Canadian Society of Endocrinology and Metabolism (CSEM) in 1973. He, along with Henry Friesen and Keith Dawson, both of McGill University, formed the first executive of the CSEM.

Dr. Bob authored several books, predominantly in the area of autoimmune disorders. He was named an Officer of the Order of Canada in 2003 which was established in 1967 to recognize outstanding achievement and service in various fields of human endeavour. The wording of his award describes him as "An internationally renowned endocrinologist and researcher, Robert Volpé was the first to highlight the role of specialized cells of the immune system in thyroid disease. The recipient of numerous awards, he has held leadership roles in many medical associations. A dedicated Volunteer and medical advisor to the Thyroid Foundation of Canada, he is known for his exemplary commitment to patient care,"

Dr. Bob was predeceased by his wife Ruth and is survived by his children, Peter, Elizabeth, Cathy, Ted and Rose Ellen.

He is dearly missed by his family, friends a people at Thyroid Foundation of Canada.

Thyroid Foundation of Canada: Presidents over the years 1980-2010

Diana Abramsky, Kingston, ON, 1980 - 1981

George Wright, Kingston, ON, 1981 - 82

J.R. Bestvater, Kingston, ON, 1982 - 84

Florence Gore, Kingston, ON, 1984- 87

Joe Boyce, Saint John, NB, 1987 - 1990

Nathalie Gifford, Kingston, ON, 1990 - 1993

Donnie Mckelvie, Saint John, NB 1993 - 1996

Arliss Beardmore, Vancouver, BC 1996 - 2000

Irene Britton, Moncton, NB, 2000 - 2002

Ed Antosz, Windsor, ON, 2002 - 2004

Ted Hawkins, Toronto, ON, 2004 - 2008

Ashok Bhaseen, Montreal, QC, 2008 - present

Memories of Yesteryear - 1988-2000

1988- TFC Board Members

1988- A journey in time

Memories of Yesteryear - 1988-2000

1989- TFC Board meeting with Acetate Sheets

1989- TFC History- Some still play a key role

Memories of Yesteryear - 1988-2000

1990- Dr. Volpe's strong commitment to TFC

1990- TFC Meeting

Memories of Yesteryear - 1988-2000

Diana and Joe Boyce, TFC President at time of photo

L-R- seated Lottie Garfield, Dr. Robert Volpe, Diana Abramsky, and Nathalie Gifford along with other TFC Board members

Memories of Yesteryear - 1988-2000

1992- They carried the flag well

1993- TFC Archives

Memories of Yesteryear - 1988-2000

1994- The dresses reflect the times

1994- TFC members at AGM

Memories of Yesteryear - 1988-2000

1994- TFC Board members at AGM

1995- TFC AGM Board members

Memories of Yesteryear - 1988-2000

1996- Glorious moment in TFC history

Ralph & Mabel Miller, daughter Catherine Fey and friends at TFC AGM, 1996.

Memories of Yesteryear - 1988-2000

1997- TFC moment- magnificent background

1998- TFC team with Dr. Volpe

Memories of Yesteryear - 1988-2000

1998- TFC Archives

1999- At the Convention Centre. The female power behind TFC

Memories of Yesteryear - 1988-2000

2000- TFC 20th Anniversary

1999- At the Convention Centre. The female power behind TFC

Diana Hains Meltzer Abramsky, C.M., B.A.

Full Name	Honour Received	Residence
Diana Hains Meltzer Abramsky, C.M., B.A.	C.M.	Kingston, Ontario
Honour	**Appointment**	**Investiture**
Member of the Order of Canada	October 25, 1990	April 17, 1991

An active volunteer with many worthwhile organizations in the Kingston area, she is to be admired for her determination in the establishment of the Thyroid Foundation of Canada, which acts as a fundraising arm for research and a support group for sufferers and their families. Her efforts have increased the medical and lay communities' awareness of this devastating disease and inspired the birth of a similar foundation in the United States.

1991- Order of Canada Award, Diana and TFC Members

Comment traite-t-on le cancer de la thyroïde, aujourd'hui ?

Martin Schlumberger, Professeur d'Oncologie à l'Université Paris-Sud, Chef du service de Médecine Nucléaire et d'Oncologie Endocrinienne à l'Institut de Cancérologie Gustave Roussy de Villejuif, France

.

L'incidence des cancers de la thyroïde augmente régulièrement depuis une trentaine d'années : cette augmentation est au moins en grande partie liée à un meilleur dépistage des nodules thyroïdiens, notamment par l'échographie.

Le cancer de la thyroïde se présente en effet le plus souvent sous la forme d'un nodule. Or, les nodules de la thyroïde sont très fréquents, et leur exploration doit permettre de repérer les nodules bénins qui sont surveillés et les cancers qui doivent être traités et qui représentent 5% environ de ces nodules : ceci repose sur le dosage de la TSH, l'échographie et la ponction à l'aiguille fine pour examen cytologique. La mise en place à l'IGR d'un accueil en 1 jour permet de faire ce bilan et de proposer une attitude de prise en charge en une seule venue.

La plupart (>90%) des cancers de la thyroïde se développent à partir des cellules vésiculaires qui normalement forment les hormones thyroïdiennes : cancer papillaire, le plus fréquent ou cancer vésiculaire. Environ 5% des cancers sont développés à partir des cellules C, ce sont les cancers médullaires de la thyroïde.

Les cancers papillaires et vésiculaires

Le traitement initial des cancers de la thyroïde est actuellement bien codifié grâce aux recommandations américaines et européennes : il repose d'abord sur la chirurgie qui comprend une thyroïdectomie totale, c'est à dire l'ablation de toute la thyroïde et en cas de cancer papillaire l'ablation des ganglions lymphatiques situés à proximité de la thyroïde. Les complications de la chirurgie sont rares et le plus souvent transitoires : paralysie récurrentielle et hypocalcémie.

Les cancers papillaires et vésiculaires…

Ce traitement est complété, sauf en cas de cancer à très faible risque de rechute, par un traitement par l'iode 131 qui est administré après stimulation par la TSH. A la suite de ce traitement initial, plus de 85% des patients sont guéris de manière définitive : l'absence de thyroïde doit être compensée par la prise d'hormone thyroïdienne, ce qui permet de remplacer parfaitement la thyroïde et un contrôle de guérison est effectué 9 à 12 mois plus tard par une échographie du cou et par un dosage de la thyroglobuline obtenu après stimulation par la TSH. Lorsque ces deux examens sont normaux, le risque de rechute à long terme est <1%. L'utilisation de la TSH recombinante humaine pendant la surveillance permet d'améliorer la qualité de vie en évitant les épisodes prolongés d'hypothyroïdie induite par le sevrage en hormones.

L'espérance de vie de ces patients est alors la même que celle de la population générale, ce qui montre que le traitement initial et la surveillance n'ont pas d'effet délétère sur la survie. Les grossesses ont un devenir identique à celui de la population générale, et ce cancer n'est pas héréditaire.

Les rechutes ganglionnaires sont traitées par l'iode 131 et par chirurgie. Les métastases à distance sont traitées par l'iode 131 en cas de fixation de l'iode radioactif par ces métastases, ce qui permet de guérir 40% de ces patients. En cas d'échec ou d'impossibilité du traitement par l'iode 131, les traitements par inhibiteurs de tyrosine kinase sont utilisés avec des résultats très prometteurs.

Les cancers médullaires

Il s'agit d'un cancer rare qui est héréditaire dans ¼ des cas, ce qui est lié à l'existence d'une anomalie génétique : la mutation du gène RET. Le traitement repose sur la chirurgie, thyroïdectomie totale et curage ganglionnaire. La chirurgie est pratiquée à un jeune âge en cas de forme héréditaire ce qui permet de prévenir l'apparition de la maladie.
La surveillance repose sur le dosage des marqueurs tumoraux, la calcitonine et l'antigène carcino-embryonnaire, et sur les examens d'imagerie. Des taux faibles sont souvent observés après le traitement initial, mais l'évolution de ce cancer est en général très lente et s'étale même en l'absence de traitement sur plusieurs décennies.

Le traitement des rechutes cervicales repose sur la chirurgie et éventuellement sur la radiothérapie externe. Le traitement des métastases à distance a progressé depuis la disponibilité des inhibiteurs de tyrosine kinase dont les premiers résultats sont très encourageants. En France, l'existence d'un réseau national TUTHYREF (Tumeurs de la Thyroïde Réfractaires) sous l'égide de l'Institut National du Cancer et coordonné par l'Institut Gustave Roussy facilite l'accès de ces patients aux progrès thérapeutiques.

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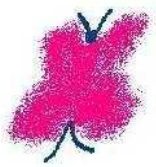

Association « Vivre sans thyroïde »

www.forum-thyroide.net

Le forum de discussion "Vivre sans thyroïde" fêtera cette année son dixième anniversaire – il a été créé en octobre 2000 par une patiente atteinte d'un cancer de la thyroïde, pour partager son expérience et aider d'autres patients à se renseigner et à échanger entre eux, afin d'affronter ces épreuves plus sereinement. Il s'agit d'une sorte de "groupe de parole" virtuel.

Connexions : plus de 3000 par jour. Utilisateurs enregistrés : près de 10.000.

Messages : environ 100 par jour

En 2007, nous avons créé une association loi 1901, pour mieux gérer et financer le forum et étendre notre rayon d'action. L'association, reconnue d'intérêt général, regroupe actuellement un peu plus de 300 membres, et se finance uniquement à partir des cotisations de ses adhérents.

Objectifs

Aider les patients récemment diagnostiqués, quelle que soit leur pathologie thyroïdienne, à comprendre leur maladie et leur expliquer ce qui va se passer. Leur permettre d'échanger avec d'autres personnes souffrant des mêmes problèmes. Ecouter et rassurer, permettre de comprendre les résultats d'analyse, d'échographie, d'opération – dédramatiser l'annonce d'un éventuel cancer. Connaître le déroulement d'une opération et d'une cure d'iode, en profitant du retour d'expérience de ceux qui sont déjà « passés par là ».

Servir de lien entre les médecins et les patients, en permettant aux professionnels de mieux appréhender le ressenti des patients, et aux patients de mieux comprendre et accepter leur maladie et leur traitement, de connaître les protocoles de suivi, les médicaments disponibles etc. Améliorer l'information du grand public sur les pathologies thyroïdiennes.

Fonctionnement

Le forum regroupe 14 rubriques différentes, pour discuter des différentes questions concernant la thyroïde (hypothyroïdie, hyperthyroïdie, Hashimoto, Basedow/Graves, nodules, opération, cancer, traitement substitutif, grossesse avec un problème thyroïdien, problèmes thyroïdiens chez les enfants …), mais aussi des questions plus générales (droits du patient : arrêt-maladie, travail, crédit/assurance …) La participation au forum est totalement

gratuite, il suffit de s'enregistrer avec un nom d'utilisateur et un mot de passe. Il est déclaré à la CNIL, et a reçu l'agrément « Health on the Net » (HON Code) pour les sites Web médicaux et de santé.

S'y ajoutent :

- Une rubrique "FAQ" ou "Foire aux questions", avec des articles répondant aux questions les plus fréquemment posées
- Une liste de liens vers d'autres sites intéressants
- Un « chat » en direct
- Des conférences grand public et des rencontres régionales/nationales et internationales entre membres du forum

- Une première antenne régionale (nous espérons que d'autres suivront bientôt !) en Ile de France, à Paris, qui organise tous les mois un « café thyroïde », rencontre amicale ouverte à tous
- La coopération internationale avec des associations de patients dans d'autres pays, au sein de la Thyroid Federation International TFI, dont le forum est membre depuis 2004, et avec des organisations de patients partout dans le monde – tout particulièrement avec des organisations au Canada, telles que la Fondation Canadienne de la Thyroïde, Thyroid Cancer Canada ...
- Des échanges d'information, via email, téléphone et courrier, avec des patients et des médecins, ainsi que la participation, tous les ans, à différents congrès : journée des cancers endocriniens à l'IGR Paris, congrès de la société française d'endocrinologie, congrès de l'European Thyroid Association ETA, World Congress on Thyroid Cancer …

L'association est gérée entièrement par des patients, tous bénévoles. Les idées ne manquent pas, juste le temps !
Mai 2010

Beate Bartès

Présidente-Fondatrice

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Le passage d'une marque à l'autre...n'est peut-être pas sans risque.

ARTICLE RÉDIGÉ PAR LE PROFESSEUR DOCTEUR M. DIETLEIN, SERVICE DE MÉDECINE NUCLÉAIRE, HÔPITAL UNIVERSITAIRE DE COLOGNE, ALLEMAGNE

La lévothyroxine (T4) est la prohormone légèrement active issue de la triiodothyronine (T3), trois fois plus active, elle-même produite par la 5' désiodase périphérique dans les organes cibles. Par un mécanisme de rétroaction négative, la baisse des concentrations de T4 libre stimule l'hypophyse pour qu'elle libère davantage de thyréostimuline (TSH) et, inversement, une hausse des concentrations de T4 abaisse la production de TSH. Aujourd'hui, les taux de TSH constituent la variable la plus sensible pour évaluer la fonction thyroïdienne. Cependant, la variation de la TSH ne peut être établie concrètement que 4 à 6 semaines après une modification de la dose de la préparation pharmaceutique de lévothyroxine (LT4).

Les hormones thyroïdiennes influent sur la croissance et le fonctionnement de presque tous les organes de l'organisme. Même une légère variation de la TSH, que ce soit en hausse ou en baisse, peut avoir des conséquences importantes, notamment durant la grossesse (retard de la maturation cérébrale du fœtus entraînant un faible QI si le taux de TSH de la mère est trop élevé), chez la personne âgée (arythmie cardiaque, fibrillation auriculaire, mortalité trois fois plus élevée si la TSH est trop faible) et lors du suivi d'un carcinome différencié de la thyroïde (risque accru de récurrence chez les patients exposés à un risque élevé si le taux de TSH peut encore être décelé).

Les évaluations de la bioéquivalence entre les différentes marques de lévothyroxine, visant à démontrer la constance thérapeutique entre les diverses préparations, doivent être examinées avec certaines réserves, car ces épreuves sont réalisées chez des sujets en bonne santé (ne présentant pas de maladie thyroïdienne) et au moyen d'un nombre limité d'échantillons et de doses supraphysiologiques. Lors de ces tests, la valeur cible n'est pas la TSH, mais le taux de T4 total. Toutefois, une variation de 12,5 % de ce taux demeure indécelable (Blakesley *et al*., 2004, *Thyroid* 14:119-200). Les variations de la biodisponibilité ont un effet linéaire sur la concentration sérique totale de T4, mais un effet exponentiel sur la concentration de TSH. Comme les personnes qui subissent les évaluations demeurent longtemps à jeun avant et après l'administration des doses de LT4 et mangent des repas normalisés, les différences possibles dans la biodisponibilité provoquées par un retard de la dissolution et de la résorption ne peuvent être détectées. Or, les variations du temps de résorption intestinale constituent un critère important dans les soins aux patients, notamment lorsque l'intervalle entre l'administration de la préparation de LT4 et le déjeuner est écourté de 15 minutes.

Aux États-Unis, la Food and Drug Administration (FDA) a resserré les critères relatifs aux nouvelles préparations génériques de lévothyroxine et a réduit la variation acceptée en matière de biodisponibilité (intervalle de confiance), passant de 90-110 % à 95-105 % (Burman *et al*., 2008, *Thyroid* 18:487-490). De plus, les diverses marques de lévothyroxine offertes aux États-Unis portent le code BX (non interchangeable) ou AB (interchangeable avec…). Ceci parce que les variations de la biodisponibilité situées entre 90 et 100 % entraînent des variations de la TSH à l'extérieur de l'intervalle de référence (Eisenberg et DiStefano, 2009, *Thyroid* 19:103-110).

Sur le marché allemand, la comparaison entre les marques de lévothyroxine produites par trois fabricants a révélé d'importantes différences quant aux taux de TSH obtenus (Wenzel et Mehrländer, 1988, *Dtsch Med Wochenschr* 113:53-58). Une étude à double insu avec répartition aléatoire et permutation réalisée récemment sur deux

médicaments de deux fabricants a révélé des différences significatives quant aux taux de T4 totale sur une période de 10 heures et à la variation de la TSH après 14 jours (Krehan *et al*., 2002, *Med Klinik* 97:522-527). D'après cette étude, ces deux marques de lévothyroxine ne peuvent être interchangées sans suivi des concentrations de TSH, en Allemagne.

Quels sont les autres facteurs connus qui influent sur la biodisponibilité? Après la conservation pendant 24 mois de comprimés de lévothyroxine à une température de 25 °C, ceux-ci ne renfermaient plus que 90 % de l'ingrédient actif original (Eisenberg et DiStefano, 2009, *Thyroid* 19:103-110). Lorsque la poudre de lévothyroxine est chauffée à 90 °C pendant 15 minutes, elle n'est pas inactivée (Wortman *et al*., 1989, *Clin Chem* 35:90-92). Divers aliments (fibres végétales, extrait de foie, extrait de soya, noix, café) et de nombreux médicaments (hydroxyde d'aluminium et de magnésium, magnésium et carbonate de calcium, sucralfate, bêtabloquants non sélectifs, hydantoïnes et inhibiteurs de la pompe à protons – pour ce dernier, les données sont contradictoires) peuvent réduire la biodisponibilité de la lévothyroxine. L'altération de l'absorption intestinale par le café a été documentée récemment (Benvenga *et al*., 2008; *Thyroid* 18:293-301).

Étonnamment, la prise de la LT4 au coucher entraîne des taux sanguins de T4 plus élevés et un effet plus puissant sur la TSH que lorsqu'elle est administrée le matin (Bolk *et al*., 2007, *Clin Endocrinol* 66:43-48).
Comme les résultats des évaluations relatives à la lévothyroxine sont discutables (examens réalisés chez des sujets en bonne santé, faible nombre d'échantillons, doses irréalistes), trois organismes américains du domaine médical (l'American Thyroid Association, l'Endocrine Society et l'American Association of Clinical Endocrinology) ont publié un énoncé de consensus dans lequel ils recommandent d'effectuer un suivi des taux de TSH après le passage à une autre marque (*Thyroid*, 2004, 14:486). Des recommandations similaires ont été émises lors d'études allemandes (Dietrich *et al*., 2008, *Dtsch Med Wochenschr* 133:1644-1648). Cependant, la réalisation de ces dosages de la TSH annulera l'épargne modérée d'environ 180 euros par année obtenue en prescrivant la lévothyroxine à 100 µg la moins chère au lieu du même médicament d'une autre marque (différence d'environ 0,5 cent par comprimé). De plus, le dosage de la TSH coûtera entre 10 et 25 euros aux assurances médicales. Si le prix des médicaments varie et que l'on tente toujours de prescrire la marque la moins chère, il peut être nécessaire de réaliser encore plus souvent ces dosages, jusqu'à plusieurs fois par année (Reiners, 2007, *Ärztezeitung*).

Conclusion
L'équilibre entre les nécessités économiques (ententes de rabais, règlement *aut idem* sur l'exécution de l'ordonnance avec le médicament le moins cher) et l'offre des soins médicaux optimaux (mêmes formes galéniques, même précision posologique) demeure fragile. Il est inutile de souligner que les écarts dans la biodisponibilité peuvent être attribuables à beaucoup d'autres causes (p. ex., conditions de conservation, intervalle entre la prise de la LT4 et celle d'autres médicaments ou suppléments alimentaires, moment de l'administration de la LT4, observance thérapeutique ou modification de la formule du médicament par le fournisseur).

Certains groupes de patients chez qui le réglage très précis de la fonction thyroïdienne est primordial peuvent être clairement déterminés, notamment les femmes enceintes atteintes d'hypothyroïdie normalisée par un médicament, les patients recevant un traitement contre un cancer de la thyroïde différencié ou les personnes âgées, chez qui une baisse de la TSH à la limite inférieure de la normale provoquée par leur médicament fera augmenter le risque de mortalité d'origine cardiovasculaire.

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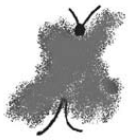
Brand Hopping ...

It might not be without risk.



ARTICLE BY PROF. DR. MED. M. DIETLEIN, DEPARTMENT OF NUCLEAR MEDICINE, UNIVERSITY HOSPITAL COLOGNE, GERMANY

Levothyroxine (T4) is the slightly active prohormone of the biologically 3 times more active triiodothyronine (T3), produced by the peripheral 5′ deiodasis in the target organs. Via a negative feedback mechanism, a decrease of free T4 will stimulate the pituitary gland to increase its production of "Thyroid Stimulating Hormone" (TSH) – and inversely, a high T4 concentration will lower the TSH. Today, the TSH value is the most sensitive laboratory value to evaluate the thyroid function. However, TSH changes will only be entirely tangible 4 to 6 weeks after a change in the LT4 dosage.

Thyroid hormones influence the growth and the function of nearly all organs of the body, and even a slight variation of the TSH, in the upper or in the lower reference range, may have serious consequences, for example during pregnancy (retardation of the fetal cerebral maturation, resulting in a lower IQ, if the TSH of the mother is too high), in elderly patients (cardiac arrhythmia, atrial fibrillation, threefold increase in cardiovascular mortality if the TSH is too low), and in the follow-up of differenciated thyroid carcinoma (higher risk of recurrence in high-risk patients if the TSH value remains detectable).

The bioequivalence evaluations on various brands of levothyroxine, aimed at demonstrating therapeutic consistency between preparations, must be considered with reservations, because these tests are performed on healthy subjects (not on thyroid patients), with a small amount of samples and with supra-physiological doses. The target value in these tests is not TSH, but total T4 – however, variations in the total T4 of 12.5% remained undetectable. (Blakesley et al. 2004, Thyroid 14:191-200). Variations in bioavailability have a linear effect on the total T4 concentration in the serum, but an exponential effect on the TSH value. As the test persons remain with an empty stomach for a long period before and after the administration of the LT4 test doses, and receive standardized meals, possible differences in the bioavailability, due to delayed dissolution and resorption, will remain undetected. However, variations in time of intestine resorption are an important criterion in patient care, when the delay between the administration of the LT4 medication and breakfast is cut down to 15 minutes.

In the USA, the FDA (Food and Drug Administration) has tightened the criteria for levothyroxine generic drugs, and narrowed the admitted variation in bioavailability (confidence interval) from 90-110% to 95-105% (Burman et al. 2008, Thyroid 18: 487-490). Furthermore, the various levothyroxine brands in the USA are rated BX (not interchangeable) or AB (interchangeable with ...). Variations in bioavailability between 90 and 110% lead to TSH variations out of the reference range (Eisenberg and DiStefano2009, Thyroid 19: 103-110).

For the German market, the comparison between the levothyroxine brands from three manufacturers showed significant differences in the TSH level (Wenzel and Mehrländer 1988, Dtsch Med Wochenschr 113:53-58). Later, a randomized double-blind cross-over study with two drugs from two manufacturers, showed significant differences in total T4 over 10 hours and in the TSH change after 14 days (Krehan et al. 2002, Med Klinik 97:522-527). According to this study, these two levothyroxine brands cannot be interchanged without TSH follow-up in Germany.

Which are the other facts with an influence on bioavailability that we know? After storing levothyroxine tablets at a temperature of 25°C for 24 month, they contain approx. 90% of the original active ingredient (Eisenberg und DiStefano 2009, Thyroid 19: 103-110). When levothyroxine powder is heated to 90°C for 15 minutes, it is not inactivated (Wortman et al. 1989, Clin Chem 35: 90-92). Various food (plant fibers, liver extract, soy bean extract, walnuts, coffee) and many drugs (aluminum and magnesium hydroxide, magnesium and calcium carbonate, sucralfate, charcoal, colestyramine, colestinol, iron sulfate, non-selective beta-blockers, hydantoin and proton pump inhibitors – for the latter, the data are contradictory) may reduce the bioavailability of levothyroxine – the possible alteration of intestine absorption by coffee has been documented recently (Benvenga et al. 2008; Thyroid 18:293-301). Surprisingly, taking LT4 at bedtime leads to higher T4 levels in the blood and to a stronger effect on the TSH value compared with taking in the morning (Bolk et al. 2007, Clin Endocrinol. 66:43-48).

(continued on page 14)

Brand Hopping *(continued from page 13)*

Due to the fact that the results of bioequivalence evaluations for levothyroxine are questionable (tests on healthy persons, small samples, unrealistic doses), three medical societies in the USA (American Thyroid Association, Endocrine Society, American Association of Clinical Endocrinology) issued a „Joint statement" recommending to follow-up the TSH value after switching brands (Thyroid 2004, 14:486). Similar recommendations were given by German studies (Dietrich et al. 2008, Dtsch Med Wochenschr 133: 1644-1648). But these recommended TSH tests will nullify the moderate saving of approx. 1.80 EUR per year which can be obtained by prescribing the cheapest levothyroxine 100 µg instead of the same drug from another manufacturer (difference per tablet approx 0.5 cents). An additional TSH test will cost the health insurances between 10 and 25 EUR. And such TSH measurements may become necessary even more often, several times a year, if drug prices vary and if one tries to prescribe always the cheapest brand (Reiners 2007, Ärztezeitung).

Conclusion

The balancing act between economic necessities (discount agreements, „aut-idem" regulation) and optimum medical care (same galenics, same accuracy of dosage) remains delicate. Needless to say that discrepancies in bioavailability may result from many other causes (e.g. storage conditions, delay between LT4 intake and other medications / dietary supplements, timing of the LT4 intake, patient compliance ... or when the supplier changes the formula of his medication). Some groups of patients, strongly depending on a very precise adjustment of their thyroid function, can be clearly defined, i.e. pregnant women with a medicamentally compensated thyroid hypofunction, patients treated for differenciated thyroid cancer, or elderly patients, for whom a TSH decrease to the lower threshold range, induced by their medication, will increase the risk of cardiovascular mortality. ❧

Letter Statement from the Brazilian Thyroid Institute

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Geraldo Medeiros-Neto, MD, MACP

(1). The "Instituto da Tiroide" is a Social Organization of Public Interest (OSIP), and is recognized officially as such by the Ministry of Justice of the Brazilian Government. Registered as OSCIP, the Instituto da Tiroide may receive donations from its members and other institutions that are tax-deductible under the terms of Law. Moreover the "Instituto da Tiroide" has to publish every year the financial details of its transactions, that have been approved by the Administrative Council and, also, to send to the Authorities all its activities for the calendar year.

(2). The Instituto da Tiroide is governed by a Board of nine members that, every four years, elect (or re-elect) the President, Secretary and Treasurer.

(3). Filiated to the Thyroid Federation International the Instituto da Tiroide has been in constant communication with other Thyroid Organizations all over the World and actively participating in the affairs of TFI.

(4). The Instituto da Tiroide has presently 1,032 members most of them patients that have thyroid disease, are under treatment or have been operated for thyroid cancer. Less than 10% of our memberships are professionals with an interest in thyroid disease (MD, nurses, biologists). The Instituto da Tiroide produces several leaflets on common thyroid diseases that are freely distributed to the lay public. Moreover the INDATIR (a short name for the Institute of thyroid) has supported the publication of three books:

1. **All you would like to know about Thyroid Cancer (2006)**
2. **Neonatal Screening for hypothyroidism (2004)**
3. **Further Advances in the Neo Natal Screening in Brazil (2008)**

These books are available to patients, doctors and public Hospitals.

(5). As part of its activities the INDATIR provided funds for young doctors to attend National and International Meetings in Thyroid Diseases. Also we partially support Thyroid Research if funds are available. Its part of INDATIR philosophy to expand knowledge on thyroid disease but also to provide means for more Research in this field.

(6). The INDATIR has a site in the internet (www.indatir.org.br) that provides information on thyroid diseases, news on recent progresses in Thyroid pathology, new treatments and results of recent studies on the field. Also the INDATIR provides an open door through duvidas@indatir.org.br (translated as doubts that you may have) for patients to obtain answers to their questions on thyroid disease, treatment and side effects.

(7). INDATIR participates in local and regional meetings of thyroid / endocrine diseases whenever we do have access to a free stand to distribute our products and ask people to join us. We look very much forward to become one of the most useful patients / doctors association with an interest in Thyroid Disease.

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A Salute to Our Volunteers

Mabel Miller: A Life of Volunteering

Mabel Miller transcends the dictionary definition of "volunteer" as "a person who enters into service of his/her own free will." Mabel's lifelong goal has been to make this world a better place; she has been volunteering as long as she can remember.

Mabel was seven years old when she joined the Junior Red Cross. Enlisted as treasurer, she saw the few pennies they collected going to help others who were less fortunate and realized at this early age what it meant to be part of a volunteer organization.

As a teenager, she volunteered with a church group and became a Sunday school facilitator. After getting married, Mabel continued volunteering with the Girl Guides. She also canvassed door to door for several organizations and assisted with various projects for the Shriners.

As soon as the youngest of her four children had started school, she also went back to work full time. For the next 22 years Mabel worked for the Canada Employment Centre as part of a management team responsible for service to clients looking for jobs or enquiring about social income.

Mabel was a founding member of the Board of Directors for a local Youth Assessment Centre for young offenders. As chairperson of the Centre's staffing committee, she viewed her task of helping make life more meaningful for young offenders as a rewarding challenge.

To survive the pressures of family, job and volunteer work, Mabel and her husband sought relaxation by moving to the country, about 25 km from Gander. No sooner had she taken her first deep breath, however, than she found herself agreeing to chair a local committee set up to look after the joint interests of a community of over 50 cottages. Five years of hard work brought many improvements to the road and the environment.

One day, Mabel noticed an article written by the late John Pinsent on thyroid disease. Having been diagnosed with a hypothyroid condition, she was pleased to see that he was organizing a meeting for those interested in learning more about the subject. Although unable to go to the meeting herself, her husband, Ralph, attended on her behalf and collected all the information presented.

Eager to share what she had learned with others suffering from thyroid disorders, Mabel formed a chapter of the Thyroid Foundation in Gander, bringing help to many people in and around her community.

"The many strides that I've seen the Thyroid Foundation make is encouraging to all involved, and I'm very thankful to the organization for the peace of mind and contentment I've been able to enjoy because of its existence.

"Juggling work, volunteering and family life has not been an easy task. However, I have never felt that any of my responsibilities was a burden. Volunteer work has enriched my life tremendously and has given me many rewarding, enjoyable and satisfying experiences that I would not have had otherwise.

"And now, with my husband and I both retired and our children all married, we are able to set our own pace. In my *spare* time, I enjoy gardening, crafts, knitting, crocheting, family activities and being outdoors.

"But one thing I will not let go for some time yet is my involvement with the Thyroid Foundation. Thank you, Diana, for creating such a worthwhile organization."

As you can appreciate, I am very proud of my Mom and the commitment she has made to the Foundation.

While looking through the thyrobulletins, I came across an article that was written on her. When I read the article, I discovered information that I have never known about "My Mom".... Needless to say I was very taken by it and I thought I would share it with you. She is indeed a special person... And as always, she continues to amaze me with what she has done in her lifetime. Catherine Fey

Visit to Gander Chapter, July 1, 2010

Mabel Miller with Gander NFL TFC Team during Ashok visit

Mabel Miller being presented with 20 Year Service Award at Gander, NFL by President Ashok Bhaseen

Farewell to Barbara

Farewell to Barb, with Dr Edmonds, Phil Morrissey , Keith, Sandy, Claudette, family and Friends on April 4th, 2010

TFC thanks Montréal en Santé publication for their help in spreading Thyroid Foundation of Canada awareness to its readers.

From the Archives: Memories of Diana

Kingston Woman's Tireless Efforts Help Continue Thyroid Research

By TOMMY Hawke
Whig-Standard Writer
Kingston, Ontario- 1990

Shortly after Diana Abramsky started the Thyroid Foundation of Canada in 1980, an unknown man came to her home on Gibson Avenue demanding to know who she thought she was, collecting money for yet another organization. "He made me feel I was being very dishonest," Ms. Abramsky says. But that did not discourage the determined Gibson Avenue housewife who had just been diagnosed with hyperthyroidism, a condition few people knew anything about.

This month the group turns 10 years old, and on June 7 was the recipient of a Trillium Foundation grant of $188,900 for use in Ontario chapters of the Thyroid Foundation. Of that, $134,700 will stay in the Kingston chapter, says Ms. Abramsky. The four-year grant is the best anniversary present the foundation could have hopes for, she says. "The past ten years haven't been easy," she says. "It was a very rough road. But the need for the group was there, and if I had to do it all over again, I would. I'm glad I did it."

In ten years, the Thyroid Foundation - which she started working out of her own bedroom and basement writing letters to various medical experts for information and soliciting funds for the new group - has grown from a "cottage industry" to national proportions, with a membership of over 2,500 in 14 chapters. She hopes to soon see an international group, with the headquarters in Kingston.

And tomorrow, the City of Kingston is hosting a citizen's reception at City Hall to honour the 10th anniversary of the founding of the rapidly growing organization. Area politicians -including Liberal MP Peter Milliken, Liberal MPP Ken Keyes, and Mayor Helen Cooper or their representatives will attend.

"The reception honours the founding members and supporters without whose talent we wouldn't have reached the stature we have today," says Ms. Abramsky.

"But everyone is welcome to attend. "We hope to see at least 100 people."

The Kingston group was the first volunteer thyroid organization in North America, and the first any where in the world for non-medical persons to address the problems of thyroid patients and to raise funds for thyroid research. "As Kingstonians and Canadians we are proud of what we have accomplished in developing our educational programs about thyroid disorders, which have helped to lessen the feelings of isolation due to ignorance about thyroid malfunction," she says. "We are very pleased to know that our ideas are catching on around the world, and that my original dream of an international thyroid foundation may be closer to realization than anyone dared to hope only a short decade ago."

Diana Meltzer Abramsky was diagnosed to be suffering from Graves disease and hyperthyroidism in 1979, quite by accident. While on a visit to her ophthalmologist, Dr. Raymond Bell, at the Kingston General Hospital for "terrible pains in her eyes, double vision, and protruding, swollen eyes," he asked her who was treating her thyroid disorder. That prompted a call to another doctor, who then made the diagnosis. "I had been sick for many years. I couldn't walk up the stairs. I couldn't lift a cup and my hands were weak. I cried a lot, and I was very nervous and high-strung. I lost weight," she says. "I was told it was in my head, that I was malingering. Misdiagnosis of thyroid disorders, Ms. Abramsky has discovered, is common. One letter she received was from a girl who had had seven electric-shock treatments because of her symptoms. "They thought she was depressed," Ms. Abramsky says. It is stories like that which have spurred the tireless worker, who still lives on Gibson Avenue, to greater aspirations. Today she is concentrating mainly on developing an international thyroid organization, and works with the local group behind the scenes.

In Kingston the group has between 150 and 180 members. Money the organization raises, which has totalled between $350,000 and $400,000 in ten years goes to funding research and educational programs. °

"We have awarded about 15 student research scholarships, which enable medical students to learn about thyroid disorders by working in thyroid research laboratories," Ms. Abramsky says. "In May, 1989, the group extended its research funding to senior professionals doing research on thyroid disorders."

Volunteers from the Thyroid Foundation will canvas the city door to door on June 11-16. Much work still needs to be done, Ms Abramsky says. "We are always looking for more volunteers."

Thyroid disorders: They're not easy to diagnose

According to Dr. Merrill Edmonds, if more people were aware of thyroid disorders, they might consider that possibility when they notice notices changes in their well-being. Dr. Merrill Edmonds heads the Division of Endocrinology and Metabolism at the University of Western Ontario's Department of Medicine. He is also a medical advisor to the Thyroid Foundation of Canada's local Chapter in London Ontario.

Dr. Edmonds states that thyroid disorders certainly have the ability to interfere with a person's quality of life. He goes on to say that the signs and symptoms can come on so subtly that many people don't realize that they are not feeling well because they don't stop to compare what they feel now to what they felt a year ago. This certainly was the case for Marjorie Miniely of London, Ontario.

At the time, Marjorie wasn't quite sure what was wrong with her. She was excessively tired all the time and could hardly get up in the morning. At times, she noticed that she was having trouble remembering simple things and that wasn't really her. She was gaining weight, slurred her speech and experienced muscle cramps and a tin-sensation in her hands and feet. She was also prone to colds which would turn into chest infections. The signs and symptoms that Marjorie was experiencing, however, were so diverse, that at times she wondered if they were real. At one point, her family even thought her problems were mental in nature as bouts of depression and anxiety would accompany her recurring physical symptoms. It wasn't her imagination, however, as her body systems were really not doing very well.

Marjorie needed medical attention and fortunately for her, she received it. Marjorie discovered that she was suffering from a medical condition in which her thyroid gland was not doing its job properly. The thyroid gland is a butterfly-shape organ and is composed of two cone-like lobes or wings. It is located in the neck, and is found below the thyroid cartilage (also known as the Adam's Apple.). The thyroid regulates the body's metabolism, growth and development and is therefore a very important organ in our bodies. Thankfully for Marjorie, once she was diagnosed and placed on medication, the signs and symptoms that she had experienced disappeared.

Today, Marjorie Miniely feels just fine.

Dr. Edmonds states that the thyroid gland basically keeps the rest of the body working at the right rate just like the cruise control regulates the constant speed of a moving vehicle.

If you are hyperthyroid, (the word hyper- means "high, beyond, excessive, above normal") this means that the thyroid is overactive, and everything in the body tends to speed up. All the cells in the body start to work overtime.

If you are hypothyroid (the word hypo means “low, under, beneath, down, below normal”) all the cells in the body slow down. With hypothyroidism, the person tends to put on weight because the body is using less energy, doesn’t produce as much heat and tends to be intolerant to the cold. The person also sleeps a lot more but still feels tired. About one in 4,000 infants are born with hypothyroidism, says Edmonds, but tests now done routinely on newborns detect the problem. The thyroid hormone secreted by the thyroid gland is important for brain development which makes early detection essential.

Research in thyroid disorders, says Edmonds, may provide scientists with clues to prevent a variety of auto-immune diseases such as arthritis and diabetes.

The Thyroid Foundation of Canada aims at raising public awareness of thyroid disorders which may go undetected for years before the person seeks help.

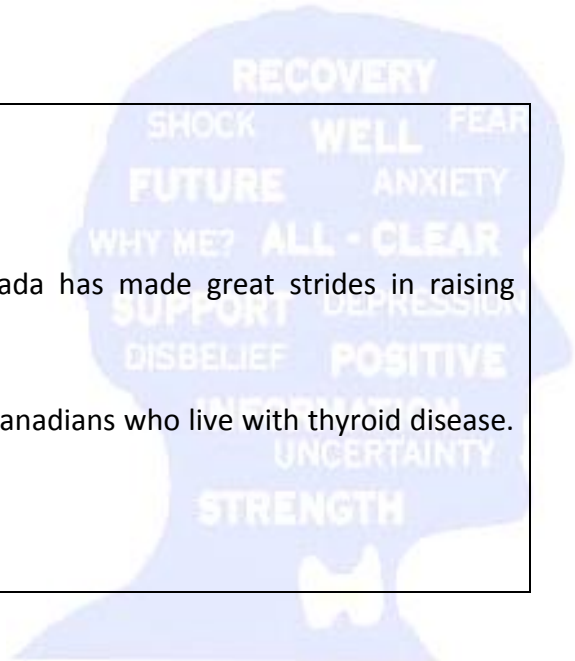
Remember!

Your membership and donations help!

Thanks to your generous support the Thyroid Foundation of Canada has made great strides in raising awareness and improving the diagnosis of thyroid disease.

We need your support to continue our work to help the millions of Canadians who live with thyroid disease.

All donations support TFC's programs



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We thank you, dear friends, colleagues and benefactors for joining us in remembering our past and celebrating our present with this very special 30th Anniversary Edition of thyrobulletin.

Together, we look forward with all of you to the future to continue our efforts to promote awareness and education about thyroid disease, lend moral support to thyroid patients and their families and to raise funds for much needed thyroid disease research.

And don't forget to put this invitation in your calendar!

Come and join us in Montreal, Qc. May 28, 2011 for our 2011 Annual Conference Details to follow.

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Congratulations and good wishes to Thyroid Foundation of Canada on the occasion of your 30th Anniversary

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