

Minutes – Annual General Meeting
May 14, 2005

Canadian Thyroid Cancer Support Group (Thy'vors) Inc.
Meeting – May 14, 2005, 9:30 a.m.
Ottawa Hospital, 1967 Riverside Drive, Ottawa

Attendees: Rita Banach, President, Toronto
Melissa Pecile, Member, Toronto
Louise Beggs, Director, Chesterville
Nola Goertz, Member, Edmonton
Tara Gallagher, Member, Toronto
Patrick Belford, Member, Toronto
Dianne Dodd, Director, Ottawa
Lorilea Erratt, Director, Chesterville
Grace Wright, Secretary-Treasurer, Toronto
Ann Dreger, Director, Aurora
Louise Rouiller, Supporter, La Prairie, QC
Sylvain Pratte, Member, La Prairie, QC
Shali Manuel, Member, Halifax
Megs Watt, Member, Halifax

Meeting was chaired by Rita Banach.

1. Call to order

Rita welcomed the attendees and affirmed that quorum had been established. Proxies were held by Rita for Beth Rajnovich (Vice-President), Gilda Tarantino (Director) and Patricia Sharkey (Member). Quorum was established with four directors in attendance and proxies held for two directors.

2. Acceptance of Agenda

MOTION: Louise Beggs SECOND: Dianne Dodd

That the Agenda of the 2005 Annual General meeting be accepted.

...PASSED

3. Acceptance of the Minutes

MOTION: Dianne Dodd SECOND: Louise Beggs

That the Minutes of the Annual General Meeting of May 1, 2004 be accepted.

...PASSED

4. President's Report

I'm pleased to say that Thy'vors has enjoyed a successful year. We have many new activities, new volunteers, and new projects on the horizon. There has been greater sharing of administrative responsibility and we have accomplished more than ever before.

In this, our fourth year of operation, we have grown to more than 500 members. We have reached up to 4,000 people through our publications and countless more through our website. We benefit from a volunteer board of directors as well as various committee members, who are growing in both in number and in strength.

Although Thyroid Cancer is a very rare form of the disease, comprising less than 1% of all cancers in Canada, it has the fastest growing rate of incidence of any cancer (over 5% more cases, on average, were diagnosed over the past ten years, while all other cancers had an incidence rise of less than 1% on average). It is therefore an ongoing battle to meet the needs of thyroid cancer survivors and to fulfill our mandate of providing information and support.

We have met our goals in several ways. Thanks to the help of **Gilda Tarantino** our distributions committee chair, we have circulated over 4,000 of each of our booklets and brochures to doctors, cancer centres and individuals since our initial printing of them just over a year ago. In March of this year for example, we sent samples of our printed matter to over 50 cancer centres across Canada. We got a good response with more than a half a dozen of the centres subsequently ordering large quantities for distribution.

Our website is not only beautiful and well laid-out, but it is also a recognized source of valuable information. I have been told by several health care professionals that it is on their recommended list for links. We owe great thanks to **Beth Rajnovich** who not only learned from scratch how to create a website, did a wonderful job of creating it, but also stays on top of keeping it current as our webmistress. This was especially evident during the flurry of events that occurred when we distributed a press release last month. Beth has also been successful in moving our site up to a higher position on search engines.

Thy'vors listserv remains our primary project and means of support. Under our talented and diligent leader -- **Patricia Sharkey**, over 3,200 messages have been posted since this time last year. We now have over 340 listserv members, representing a jump of more than 125 people from last year. It is an amazing and well-appreciated resource. An adjunct project of the listserv is our seasonal newsletter. Until recently, the newsletter was only available in e-mail format. With the latest edition, we have improved our service and now also produce the newsletter formatted for print. With this new format we can mail copies to our supporters, MAP members, and perhaps most importantly, to our 25 members who currently do not have internet access. As well, we have made it available in PDF format for more usable and attractive reading on our website or by e-mail attachment.

Our in-person activities over the last year included a National Cancer Survivor's Day Event in Halifax. Beth represented us at this event last June. In October last year, our brand new display board was used at an event in Oakville. The forum included a well attended seminar on Hypothyroidism sponsored by the Hamilton-Burlington Chapter of

the Thyroid Foundation of Canada. In November, **Kim McNally** and I attended the TFC Gala, at which time I had the opportunity to chat briefly with Dr. Dreidger and to speak with Dr. Volpe, who we recently lost due to illness. In April of this year, thanks to **Myra Fan** we held a very successful Con-Neck-ion get-together in Toronto which was attended by 23 people despite a late spring snow storm.

Although we did not receive any large grants this year, we did manage to maintain a bank balance of over \$5,000. Much of these funds can be attributed to small donations of up to \$500 made by our own members and other donations made in memory of Wally Patching, as well as donations received by doctors such as \$800 in total from U of Ottawa Medical Associates, \$150 from Health Care Management Associates (Dr. A. Dreidger), Telus (\$300), and others.

The Weekly Update continued to serve us well this year as a form of virtual weekly board meeting. Practically every week there were several things to report on and decisions to be made within the group. For example, this year we entered into a large discussion about in-person get-togethers. Although a seemingly straightforward topic, the pursuant conversation touched upon issues that went to the core of how we define ourselves as a support organization. I thank you for your input into this administrative function.

And speaking of admin... I thank both **Beth Rajnovich** and **Grace Wright**, the other members of the executive of Thry'vors. Both of them are there for me when I have a question or need for support. Grace also does a fantastic job as treasurer, so great in fact that we went without the services of a separate person for bookkeeping this year. She also acknowledges all individual donations not only with a tax receipt, but also with a lovely card or letter of thanks. She does a wonderful job at making our donors feel acknowledged and thanked.

We were very fortunate this year to have an active and hardworking AGM committee. The committee met weekly for most of the year to plan the event. We are here today enjoying not only our annual meeting, but a great line up of events and speakers in the form of a min-conference because of the hard work of **Louise Beggs**, **Dianne Dodd** and **Lorilea Erratt**.

We struck some new partnerships this year. Linda Boyle, TV journalist and thyroid cancer survivor, kept us in mind when she organized a *Health on the Line* TV broadcast with Avery Haines last fall. Our own **Ann Dreger** was the featured guest on Avery's one hour program. As well, Olivia Chow, Toronto City Councillor and wife of the Federal NDP leader Jack Layton, "came-out" as a thyroid cancer survivor last month just in time to coincide with the Canadian Cancer Society's cancer statistics release. She, and her PR people, graciously helped us put together a news release which brought about a good deal of media attention to thyroid cancer and to our group. Olivia has also offered to help out with future events and fundraising.

Fortunately this was also a good year for the administration of Thry'vors. Several people have stepped forward to help in key roles within the organization. **Liana Keller** for example, is our e-mail intake person. She reads, responds and coordinates the follow-up for people who reach us by e-mail. **Myra Fan** has taken on the responsibility of getting

our membership list in shape and following up on people who have contacted us in one way or another over the past 3 years. **Steve Saines** has been writing members of parliament (Ontario) to educate them on the need to have OHIP coverage of Thyrogen. He is also looking at the issues of CT/PET scanning coverage. **Lynda Murtha** has initiated a new project called "Ask Thy'vors" whereby our members are now able to ask medical, emotional or pharmaceutical questions of our Medical Advisory Panel. **Jennifer Prober** has very generously offered to operate a fundraising project in 4 McDonald's Restaurant locations in the Strafford/London area during June. We look forward to the possibility of this being an annual funding partnership with McDonald's. And very recently, a new volunteer came forward to step into the position of Liaison Committee Coordinator. **Jasna Schwind** will now be our rep to the TFC, CCAN and others.

We also thank our outgoing board members. **Dianne Dodd** and **Kim McNally** are both individuals who were founding members of Thy'vors. Their contributions have been great. Kim was there for our birth, as we first started as a group through our early relationship with the Thyroid Foundation in Kingston. Dianne helped create our initial group policies and was instrumental in the development and writing of our booklet. We don't say goodbye as they will continue as members of Thy'vors, we just thank them for the contributions they have made to the board of directors.

And lastly I extend a warm welcome to our new board members, **Louise Beggs, Ann Dreger** and **Myra Fan**. You have already made great contributions to our group and I am sure we will see more wonderful things in 2005-2006.

Looking ahead I see great promise for Thy'vors. We're stronger; we're better organized, and we're well on our way.

With thanks.

MOTION: Grace Wright SECOND: Lorilea Errat

That the President's Report be accepted.

...PASSED

5. Treasurer's Report

Grace presented the financial statements for the year ended December 31, 2004. The proposed budgeted allocation of funds for the coming year was explained and the current account balance was provided.

MOTION: Lorilea Errat SECOND: Shali Manuel

That the Treasurer's report be accepted.

...PASSED

6. Acceptance of the new slate of Directors

The following was presented as the list of proposed Directors for 2005-2006:

Rita Banach,	President/Officer
Louise Beggs	Director
Ann Dreger	Director
Lorilea Erratt	Director
Myra Fan	Director
Beth Rajnovich	Vice-President/Officer
Gilda Tarantino	Director
Grace Wright	Secretary-Treasurer/Officer

Rita provided a clarification of the roles of those on the slate of Directors. Megan Watt nominated Shali Manuel as a Director for 2005-2006. Shali introduced herself as thyroid cancer survivor, currently pursuing graduate studies in health education. Shali Manuel's name was added to the proposed list of Directors for 2005-2006.

The acceptance was put to a vote to all in attendance.

That the proposed list of Directors for 2005-2006, as amended to include the newly nominated Shali Manuel, be accepted.

...PASSED UNANIMOUSLY

7. Other business

There were no items introduced at this point.

8. Adjournment

With no further business, Rita invited that the 2005 Annual General Meeting be adjourned at 10:30.

MOTION: Louise Beggs SECOND: Ann Dreger

That the 2005 Annual General Meeting be adjourned.

...PASSED

Minutes prepared by Grace Wright, Secretary

Minutes – General Business Meeting
May 14, 2005

Canadian Thyroid Cancer Support Group (Thry'vors) Inc.
Meeting – May 14, 2005, 10:45 a.m.
Ottawa Hospital, 1967 Riversides Drive, Ottawa

Attendees: Rita Banach, President, Toronto
Melissa Pecile, Member, Toronto
Louise Beggs, Director, Chesterville
Nola Goertz, Member, Edmonton
Tara Gallagher, Member, Toronto
Patrick Belford, Member, Toronto
Dianne Dodd, Director, Ottawa
Lorilea Erratt, Director, Chesterville
Grace Wright, Secretary-Treasurer, Toronto
Ann Dreger, Director, Aurora
Louise Rouiller, Supporter, La Prairie, QC
Sylvain Pratte, Member, La Prairie, QC
Shali Manuel, Member, Halifax
Megs Watt, Member, Halifax

1. Call to order and Review of Action Items from the 2004 AGM

Rita proposed that, with all attendees present, the meeting begin earlier than scheduled. Rita was satisfied to report that the all but three of the action items from the previous year's meeting had been fulfilled. The three outstanding items are: the review of a membership fee; the development and provision of resources for the medullary group; and, the development of a strategic plan.

Membership Fee:

The advantage of applying a membership fee would be in its being a reliable source of income. The previous obstacle of not being able to provide paying members with a tangible benefit could now be overcome by the provision of the seasonal newsletter. (The success of the newsletter was applauded by Meg who compared it favourably with that of other patient support groups.) It was suggested that the challenges of administering a membership fee for a base of 500 members, with such functions as processing, follow-up, enforcement and the determination of possible levels of membership, might be too onerous for volunteers to handle. Louise emphasized concern over the required volunteer resources to process the fee. For income purposes, the alternative may be in asking new members to make a donation when they join. Lorilea suggested that during June, a request for support might be made to all current members. This appeal for support may be also made through a mailing to members. Myra Fan is in the process of compiling a list of members' addressed by calling those who are not currently active on the listserv. There is the option of the making the appeal by email.

ACTION ITEM: To create an appeal to all members which will go out in June 2006. This will entail: asking Patricia about the viability of asking the members of the listserv to send us mailing addresses; sending an electronic version of the Newsletter marked as a Special Notice; determining how best to reach as many members as possible; exploring web-based capabilities (Grace).

Medullary Group Resources:

Thry'vors has twelve (12) current members living with medullary thyroid cancer. Their information and support needs are very different from those of members with other forms of thyca. The Medullary thyca group requires a co-ordinator with first-hand experience with med. thyca.

ACTION ITEM: This item will remain on hold until Thry'vors has more human resources. To be reviewed at the 2006 AGM.

Strategic Plan:

Nancy Williams had created an outline of the Strategic Plan for Thry'vors. Shali volunteered to further the work on the draft and to make recommendations for the Plan.

ACTION ITEM: The Strategic plan will be reviewed and recommendations will be submitted. (Shali).

2. Media Committee Terms of Reference:

Ann is the new coordinator of the Media Committee and presented the five (5) recommendations - diligently established by Diane Patching, the former committee co-ordinator – as follows:

1. to build awareness of thyroid cancer (diagnosis, patient support, treatment, and research)
2. to identify journalists and health reporting organizations who may be interested in doing a story on thyroid cancer
3. to create news releases and background material for distribution to media in order to facilitate storyline pick-up and program development
4. to bring together patients, medical professionals and other willing to speak to the media about thyroid cancer
5. to prepare and distribute material to the media as part of the Thyroid Month (June) and in conjunction with the Canadian Cancer Society's annual cancer statistics release (April)

The participation of the doctors (such as Dr. Driedger and Dr. Rosen) on the Media Committee increases the credibility of its activities.

ACTION ITEM: To add the formal participation of medical professionals to the purpose of the Media Committee (Ann).

Coinciding with the April 2005 release of the CCS statistics, Toronto politician, Olivia Chow, provided the media (nation-wide) with the story of her own diagnosis of thyca. The potential for increased profile and awareness of thyca through such stories has provided the Media Committee with motivation and encouragement for compiling a list of members to be contacted for human interest and personal account stories.

ACTION ITEM: To establish a list of Thyry'vors members who will be available to speak with media.

ACTION ITEM: To establish a list of contacts at local and national media agencies for media releases (Ann, May 2005).

3. Funding Protocol and Other Funding Issues

Rita explained that member Jennifer Prober, owner of 3 McDonalds restaurants in the Stratford/London area in Ontario, has initiated a two-fold fundraising event at her restaurants (and a fourth owned by a friend) whereby: donation boxes will be placed at drive-through windows, collecting funds for Thyry'vors; and educational brochure stands will be placed inside the restaurants at the order/cash counter. Much discussion followed concerning the content and production of the leaflet for this distribution. The opportunity provided by Jennifer was gratefully received by all present and it was seen as an opportunity to fine-tune the leaflet for wider distribution. Concerns over the potential of a perceived alignment between Thyry'vors and McDonald's organization were explored, however the advantages of increasing awareness of thyca and the activities of Thyry'vors were ultimately seen as superseding those concerns.

ACTION ITEM: To contact thyroid specialists in the GTA for statistics regarding Canadians currently living with thyca (Grace).

ACTION ITEM: The leaflet will be translated into French and means of distribution among French-speaking communities will be explored (Joanna).

Tara introduced a fundraising/awareness opportunity through Harlequin publications.

ACTION ITEM: To determine the distribution possibility for the Thyry'vors leaflet/brochure through Harlequin publishers (Tara).

Grace briefly explained the procedure followed for processing donations. It was suggested that Thyry'vors be able to accept donations on-line.

ACTION ITEM: To explore the services available (eg. PayPal) for receiving donations on-line (Grace).

Rita opened the discussion concerning the current policy on Corporate Endorsements and Fundraising, which is set as follows:

Thry'vors does not endorse any product, medication, method of treatment or service in the diagnosis, treatment, medical care or monitoring of thyroid cancer. In its fundraising activities, Thry'vors will endeavour to achieve a balance between membership fees, corporate and individual donations and government-based funding. At no time, shall funds received from pharmaceutical companies selling products used in the care of thyroid cancer, in particular those companies launching new products in the diagnosis, treatment, and monitoring of thyroid cancer, comprise more than 30% of Thry'vors' budget.

In anticipation of the required reprinting of the well-received Thry'vors booklet, funding requests had been prepared and submitted by Rita to several organizations in various sectors. An early response had been received from Genzyme Canada Inc. Support from Genzyme would potentially represent more than 30% of our current budget. It was determined that project-specific funding should not fall under the policy as above. Dianne strongly reminded the attendees of the spirit and intentions behind the original establishment of this policy.

MOTION: Louise

That the Policy on Corporate Endorsements and Fundraising be amended to read, in its final sentence, "comprise more than 30% of Thry'vors' operational budget".

...PASSED

MOTION: Louise

That Thry'vors will accept funding for Capital Expenses from pharmaceutical companies.

...PASSED

Donor recognition was next addressed. The credibility of Thry'vors resources is, according to member, patient and doctor feedback, due in part to its production by a body other than a pharmaceutical. Therefore, it was put forward that Thry'vors should not include mention of sponsorship in its published materials. Relative to the Booklet, two options for donor recognition were explored: (a) listing booklet sponsors in a standard font, with no corporate logos; (b) general expression of gratitude to booklet sponsors, with a direction to the donor recognition page on the Thry'vors website. The matter was put to a general vote to the twelve (12) in attendance.

(a) listing booklet sponsors in a standard font, with no corporate logos

VOTES FOR: 3 (plus 3 proxy votes) = 6

(b) general expression of gratitude to booklet sponsors, with a direction to the donor recognition page on the Thry'vors website

VOTES FOR: 9

With the result of the vote the following policy for donor recognition of sponsors of the publication of the booklet would in the form of a general expression of gratitude to the sponsors of the booklet, with a direction to the donor recognition page at www.thryvors.org.

(Note: On May 16th, in a subsequent vote of the same persons available at the business meeting, it was decided to receive a donation offer made by Genzyme of \$5,000, and to acknowledge it in writing in the booklet)

4. Committee Reports

Attendees were asked to read the printed reports as submitted by each of the committees and feedback was encouraged and invited.

5. DVDs and CD available

Rita presented the DVDs currently available for purchase. Features include the interview of Ann Dreger by Avery Haines and the television appearance of Olivia Chow in April.

6. Other business

Nola suggested that Thry'vors create and make available for purchase/distribution a ribbon to raise awareness of the thyca and Thry'vors. Alternate forms, such as a butterfly pin were discussed.

ACTION ITEM: To invite designs and suggestions for a small, wearable ribbon or pin to symbolize our activities and raise awareness of thyca.

7. Adjournment

With no further business, the General Business Meeting was adjourned.

Minutes prepared by Grace Wright, Secretary