

Minutes - Annual General Meeting
May 1, 2004

Canadian Thyroid Cancer Support Group (Thry'vors) Inc.
Meeting - May 1, 2004, 10:00 a.m.
Wellspring Halton-Peel, 2545 Sixth Line, Oakville

Attendees: Rita Banach, President, Toronto
Nancy Williams, Vice President, Oakville
Grace Wright, Secretary/Treasurer, Toronto
Dianne Dodd, Director, Ottawa
Beth Rajnovich, Director, Bedford, NS (by phone)
Lorilea Erratt, Member, Chesterville
Diane Patching, Director, Orangeville
Louise Beggs, Member, Stittsville
Ann Dreger, Member, Aurora
Kathy Goode, Member, Mississauga
Biljana Magazin, Member, Ottawa
Donna Murray, Member, St. Thomas
Jody Smith, Member, Dundroon
Rob Smith, Member, Dundroon
Yiannoula Voulgaris, Member, Scarborough
Lynda Murtha, Member, Toronto

Meeting was chaired by Rita Banach.

1. Call to order

Rita welcomed the attendees and affirmed that quorum had been established. Three proxy statements were accepted, signed by Debbie Langdon (proxy given to Rita Banach), Patricia Sharkey (proxy given to Rita Banach) and Kim McNally (proxy given to Dianne Dodd). Rita initiated introductions of those in attendance.

2. Acceptance of Agenda

Rita pointed out that the agenda had been amended to accommodate a 2:30 start for the Wellness Workshop in the afternoon.

MOTION: Nancy Williams SECOND: Dianne Dodd

That the Agenda of the Annual General Meeting be accepted.

... PASSED

3. Acceptance of the Minutes

MOTION: Kathy Goode

SECOND: Diane Patching

That the Minutes of the Annual General Meeting of May 31, 2003 be accepted.

... PASSED

4. Presidents Report

Being president of Thy'vors is both a challenge and a privilege. It brings into play all of my abilities and causes me to develop some new ones. It gives me the opportunity to work daily with an incredibly strong group of people -- people who want what I want which is to support Thyroid Cancer survivors both with information and kindness.

The past year has seen tremendous growth in Thy'vors. Over the summer of 2003 we achieved two large goals: our application to the Canada Revenue Agency for designation as a charitable organization was accepted, and our application for funding to the Ontario Trillium Foundation was equally successful.

With charitable status we have been able to offer tax receipts for donations, and they have started to come from our members and friends. Even small donations add up and they are much appreciated. Because of our new status, we will be able to approach charitable foundations in the future for their support. As well, the obtainment of charitable status simultaneously strengthened our application to Trillium.

Our \$14,000 grant from the Ontario Trillium Foundation supported the design, publication and distribution of new brochures and the development of a booklet *A Patients Guide to Thyroid Cancer for those diagnosed with papillary, follicular or hurthle cell cancers*. The grant also helped to support our website development and other expenses.

We benefited from two in-kind donations of mailing lists. One, from Theramed Corporation, and the other from Scotts Directories. Although the lists had some overlap, they each had mutually exclusive names as well, and made for a very strong initial mailing of our two new publications and an order form, to 450 doctors specializing in the field of Thyroid Cancer across Canada.

Our deliverables for the grant from Trillium included: the establishment and use of a medical advisory panel, and the development and dissemination of 2,000 brochures and 1,300 booklets. We successfully established a medical panel very early on in the project, and had expertise of six physicians involved in the field of thyroid disease or psychiatry to rely on for review of our written material and to call upon for advice and guidance. To date, we have surpassed the distribution goal for booklets and we will soon pass the goal for brochures as well, putting us ahead of schedule for meeting the deliverables of the Trillium grant. Our grant period ends in September this year.

Many thanks go to the writing committee for the Trillium application and especially to the writing and editing committee for the brochure and booklet. It is no exaggeration to say that Dianne Dodd, Patricia Sharkey, Nancy Williams, Jean Kiegerl, Theresa de Jeu and I, went through at least 30 drafts over several months before we came up with the finished product. Once the medical panel added their constructive comments, we also benefited from the edits provided by Rhona Goodspeed. Rhona is a colleague of Diannes whose comments added a final refinement to our products.

The brochures and booklets have been positively received by doctors working with thyroid cancer patients. In the short few weeks since our pilot mailing, their orders for these products have ranged from a request for 8 copies, to one for 200 copies of each. The doctors' comments have included: "Excellent booklet", "They were really needed!", and "Great initiative."

Another big project undertaken this year has been our website. Beth Rajnovich and her partner Chris took it upon themselves to learn how to create a website and made one for us that looks both professional and beautiful. It is an excellent source of information and resources for all Canadians with thyroid cancer. I think Beth and Chris have created something that survivors will greatly appreciate and for which we can all be very proud to be associated with.

Thry'vors biggest and most important project continues to be our listserv. Regular users of the listserv know they can count on Patricia Sharkey, the listserv coordinator, to pull from her vast knowledge and collected files to provide information for just about any question asked. We all know her as a tremendous source of information and support. What many may not be aware of, is the enormous amount of time and backstage work that goes into operating the listserv and dealing with issues, both technical and emotional, that occur on almost a daily basis. Patricia, with the help of her committee members (Lynda, Kim, Jim, Nancy, Donna, Diane, Katie and myself), have put thousands of volunteer hours of work into our listserv. Patricia also helps with many other Thry'vors projects and initiatives and I would like to acknowledge her tremendous contribution to our organization.

Speaking of back stage work, Nancy Williams has been both the Vice-President and great friend this year. Nancy and I communicated almost daily this year on a multitude of Thry'vors-related subjects. She too has put hundreds of hours of volunteer time into this organization and has been a wealth of knowledge especially about organizational issues. Much of her contribution has not been obvious to the members but it certainly was to me, and I will greatly miss her contribution and support as she moves on to other things next year.

As we became a charitable organization and received a large grant this year, financial issues and bookkeeping became important for the first time. We have been very fortunate to have Grace Wright as our treasurer. Amongst the variety of contributions she makes to Thry'vors, she also keeps our books and issues charitable receipts. She set up a system whereby financial contributions are not only acknowledged with a

receipt, but she also writes a lovely and personal thank you note to each donor. Grace has also been the liaison to Sharleen Walker, a member of Thry'vors, who evaluated our financial records in order to produce financial statements. With her valuable help, we will be able to report financial information to our members, funders and the federal government.

There are also many other members of our group who make very significant contributions to Thry'vors. Dianne Dodd has acted as our liaison person to the *Thyroid Foundation of Canada* and to the *CCAN Canadian Cancer Advocates Network*. Diane Patching has been our media & communication person and has been a valuable link to corporations such as Theramed/Genzyme. She and Patricia Sharkey worked together to produce a media release last year, which although nicely executed, was not readily picked up by the media as the timing corresponded with the SARS crisis.

There are several other people who work behind the scenes at Thry'vors putting in a great deal of time doing 'front-line' work. People like Debbie Langdon, Kim McNally, Patricia Sharkey, Nancy Williams and Dianne Dodd, to name a few, can be counted on to provide support mainly through one-on-one telephone conversations with people who contact us. I act somewhat as an intake worker by receiving calls on our answering machine, responding to the callers myself, or passing their contact information to others as need be. One person needs to be singled out as our special star in this regard. That person is Lynda Murtha. Even though Lynda has gone through a very bad year in regards to her own health, she has never turned me down when I asked her to return a call to someone who has contacted us and needs support. Lynda has a very special gift she is compassionate and supportive even with, or perhaps especially with, those who have more difficult-to-treat forms of thyroid cancer people for which there are no other specialized support services. I sincerely thank all of you who have participated and given of yourself so generously in this way.

Speaking of support, one of our most supportive people this year has been Diane Patching. She has given so much to our group in many ways and did so, while she herself is not a thyroid cancer patient but rather was the spouse of one. She continued to work tirelessly for our cause through supporting our initiatives, writing letters, participating with CCAN and numerous other ways, even whilst her dear late husband Wally, was succumbing to thyroid cancer himself. Although I personally never met Wally, I feel as if I knew him through Diane. His love for Diane, his bravery and his sense of humour will always stand out for me.

At this time I'd like to make an announcement. Nancy and I would like to add an item to today's agenda. We would like to propose that in Wally Patching's honour, we establish an annual lecture. We envision that as Thry'vors grows as an organization that we will be able to invite speakers to our yearly AGM, much as we did last year. We would like to suggest that at future meetings or conferences, that we designate that one of the presentations or lectures, or the keynote speaker, be regarded as the *Wally Patching Memorial Lecture*. We invite you to vote on this item later in today's agenda.

Lastly, I look ahead to next year. As new people join our listserv, our group and our board of directors, we become stronger. A great example of this is in Gilda Tarantino who has already made a very significant contribution to Thry'vors through her overseeing of the distribution of our published material. I greatly look forward to the contributions that she and our other new board member, Lorilea Errat will make to our group this year.

I congratulate you and thank you to all for the tremendous contributions you have made to Thry'vors this year, and for the ones to come next year.

MOTION: Dianne Dodd SECOND: Beth Rajnovich

That the Presidents report be accepted.

... PASSED

5. Treasurers Report

Grace presented the financial statements for the year ended December 31, 2003 as prepared by Sharlene Walker. Clarification was requested regarding the deferring of revenue from the Trillium grant (deferred to the year ending Dec. 31, 2004) and the classification of postage expenses.

Grace outlined the current record-keeping procedures of donations, and at Rita's prompting, suggested further discussion about establishing organized efforts for approaching corporations for funding.

MOTION: Nancy Williams SECOND: Diane Patching

That the Treasurers report be accepted.

... PASSED

6. Acceptance of the new slate of Directors.

The following was presented as the list of proposed Directors for 2004-2005:

Rita Banach	President
Beth Rajnovich	Vice-President
Grace Wright	Secretary-Treasurer
Dianne Dodd	Director
Gilda Tarrantino	Director
Lorilea Errat	Director

MOTION: Diane Patching SECOND: Kathy Goode

That the proposed list of Directors for 2004-2005 be accepted.

... PASSED

7. Other Business

Beth Rajnovich reported from Halifax to the group assembled around a speaker-phone. Following up on the decision at the 2003 AGM to create a Thry'vors website, Beth and her partner Chris worked from May until September of 2003 creating the mock-up and content of the site. On September 28, 2003 the website was launched on the internet - just as hurricane Juan was hitting the city of Halifax. Since the launch there have been several additions including content material and the booklet (in both PDF and text formats). Currently in development are pop-up menus. The costs associated with the website are: \$10.00 annual domain registration fee; and, \$150.00 annual web-site hosting fee. Beth explained that the two major challenges she faces are keeping the web-site up-to-date and making it easier to find on the net. Beth thanked everyone for the positive feedback that has been provided.

8. Adjournment

With no further business, Rita adjourned the 2004 Annual General Meeting at 10:40 am.

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Yiannoula Voulgaris, Member, Scarborough
Lynda Murtha, Member, Toronto
Azim Daya, Member, Toronto

1. Call to order and review of action items.

Rita Banach accepted the minutes of the 2003 Business Meeting and began the review of the Action Items set out at the previous years general business meeting - these are presented below (in italics: *2003 AI*) in conjunction with the relevant committee reports.

2. Membership Fee

2003 AI: Requirement of a membership fee is to be assessed at a later time: The possibility of requesting a membership fee from active members was deferred again until next year as Thry'vors does not offer a tangible benefit in return (i.e. a printed and mailed copy of a newsletter for example). The relevant issues discussed were: the distinction between participants and members; privacy policy; provision of a newsletter published in hardcopy for paying members. It was determined that the assessment of the viability of a membership fee could be an area of interest to potential donors.

NEW ACTION ITEM: To establish a team of volunteers to establish a protocol of membership.

3. Committee Reports

A. Executive -- Rita

From the By-laws of our organization (2003), the Executive is defined and empowered as follows:

- 10.1 Subject to the provisions of the Act, the Board shall appoint a President, Vice-President, Treasurer, Secretary and such other Officers as the Board may determine. The Officers shall comprise the Executive Committee as needed. The board may specify the duties of, and delegate to such Officers powers to manage the business and affairs of Thry'vors. An Officer shall be a Director.
- 10.3 As need be, the Executive Committee shall between meetings of the Board perform the duties and exercise the power of the Board, except those duties and power which by law must be performed by the Board and subject to any restrictions imposed by the Board. The Executive Committee shall report all actions to the Board at the next meeting of the Board.

Rita reiterated that the Executive Committee for 2004/2005 would be Rita Banach as President, Beth Rajnovich as Vice President, and Grace Wright as Secretary-Treasurer. The Executive meets and/or communicates to make decisions for the direction of Thry'vors when a meeting of the whole Board is impossible. Over the last year, Rita has posted a weekly report of activities and issues relevant to the Board - Rita was pleased, and surprised, that the weekly report included important news almost every week.

B. Finance -- Grace

Grace referred to the financial statement reviewed during the AGM.

2003 AI: Rita to prepare a 2-page funding proposal for submission to ten prospective donors: The proposal was prepared however funding efforts were successfully focused on securing support from the Trillium Foundation.

NEW ACTION ITEM: Fundraising efforts to expand to include corporate donors. Grace to coordinate a team of volunteers to assist in compiling a list of appropriate prospective donors and to submit two-page proposal to those donors.

B. a. Website -- Rita

2003 AI: The glossary of acronyms and terminology will be added to the file section of the listserv: A glossary continues to be compiled by Rita, based on the American N.C.I. glossary, with additions relevant to Canadian cancer issues and treatment.

NEW ACTION ITEM: The finalized glossary will be circulated among Board members and after which it will be added to the website.

B. b. Listserv - Rita

Rita read the report of the Listserv Committee, as prepared by Patricia Sharkey. The mini-bios have been found to be valuable and comforting to members. The mini-bios should be updated by those who have posted them. It was suggested that more moderators are required.

C. Medullary Group Report - Rita

(See attached report, Appendix F) As Thy'vors is seeing an increase in members seeking support after a diagnosis of medullary thyrca, sustainable leadership of a medullary group is needed. While such members are currently directed to the listserv, it was decided that we would wait to see if medullary thyrca patients want to organize a sub-group (the current group has five members).

It was also discussed whether a doctor should be asked to draft medullary-relevant material or if we might 'Canadian-ize' the available material from the U.S. for medullary patients in Canada.

NEW ACTION ITEM: Rita is to ask Dr. Shereen Ezzat for his opinion about developing a patient resource on medullary thyrca.

NEW ACTION ITEM: Nancy to inform Beth of the website link to information on Canadian clinical trials, as published in the May 2004 issue of Canadian Living.

NEW ACTION ITEM: to consider future development of a chat function if a doctor is available.

NEW ACTION ITEM: Nancy to develop an FAQ on the LID, but exclude recipes.

D. Publications & Distribution -- Rita

2003 AI: Formally establish a Booklet Committee. Feedback on the draft of the booklet will be collected and tabulated by Dianne:

Thy'vors has withdrawn from the Patient Information Package project for a variety of reasons. The TFC may be continuing to distribute brochures in kit form. (see Appendix E)

Thy'vors is currently distributing our material directly to doctors. Members are encouraged to help in distribution to GPs and endocrinologists.

NEW ACTION ITEM: Members will be invited to submit to Rita doctors' names, addresses and number of copies of new brochure and or booklets requested.

2003 AI: Theresa and Grace will provide the committee with potential contacts for the distribution of our new brochure to regional cancer centres across Canada: The compilation of a contact list was remanded as an action item for 2004/2005 and Grace will help ensure that the newly published booklet and pamphlet will be distributed among the RCCs across Canada.

E. Media/Communications -- Diane Patching

Due to the media attention drawn by SARS in April 2003, the media release prepared by Thy'vors - timed to coincide with the release of the Canadian cancer statistics did not garner very much response from the media. Diane suggested that we approach television media rather than print, and it was suggested that Gilda might be able to facilitate this approach. Rita, noting that June is thyroid month, urged that Thy'vors try to coordinate another media release. The distinction between rates of incidence and those of prevalence should be made clear in any material prepared for media. Louise suggested that recruiting a spokesperson might help to draw media attention to our efforts. Some individuals named included Emma Robinson, Linda Boyle and Marilyn Lastman. Diane will be available to resume her role on this committee after she settles in her new home (after July 1).

NEW ACTION ITEM: Donna Murray to work on a media release for June (Thyroid month) and to coordinate its release with Theramed. Louise Beggs to support work on the Media/Communications committee.

(Note: Subsequent to the meeting, Donna reported that she would be unable to carry through with this task)

F. Medical Advisory Panel -- Dianne

2003 AI: Establish a medical advisory panel: A panel was established and their contributions to the booklet were valuable to its content.

Dianne reported that the panel is working well. She requested that the contact person be a Listserv moderator to ensure that this individual is in constant contact with the activities on the Listserv. Diane P. volunteered for this role as of July 1, 2004.

G. Liaison Partners -- Dianne

2003 AI: Dianne would investigate the viability of engaging in advocacy activities through the Canadian Cancer Advocacy Network: (The limitations of political and/or advocacy activities imposed by the status of registered charity have been established at 10%.)

Dianne reviewed her work as liaison with CCAN and handed out a 1-page outline of the Canadian Cancer Strategy, encouraging Thry'vors to write to local MPs and senators regarding cancer issues, such as waiting times, and PET scan availabilities -- as individuals concerned about these issues. She explained why Thry'vors benefits from our association with CCAN. Rita suggested that Donna's committee coordinate its efforts with CCAN via Dianne. Dianne asked everyone to let her know who will write letters (note: letters must be written on personal letterhead; not Thry'vors)

Dianne has served as liaison with the TFC for two years, providing an efficient channel of information to Thry'vors and its members. The issue of the patient information kit was revisited. Dianne will be attending the TFC AGM in June. Ted Hawkins has been newly appointed as the president of the TFC.

NEW ACTION ITEM: The committee is to coordinate with CCAN regarding advocacy (in view of upcoming election). Relevant issues include home-care, waiting lists and waiting times. *Can we link to advocacy sites without compromising federal charitable organization status.*

Before proceeding with discussion for the 2005 AGM, Rita thanked Quiznos, (Oakville) for donating a platter of sandwiches for our lunch.

H. 2005 AGM Organizing Committee -- Dianne

2003 AI: On-line vote will be held in six months to decide on the host city and to invite members to volunteer as meeting organizers. It was decided that the 2004 meeting would be held in Oakville.

It was decided that the 2005 AGM would be held in Ottawa and that the organizing committee include Lorilea, Louise and Dianne. Corporate sponsorship of part of the AGM public forums will be explored by the organizing committee and any sponsorship secured will need to be transparent and enhance the quality of the patient information and experience. The committee will report their recommendations to the board in about 6 month's time for further discussion.

The proposal, put forth by Rita Banach and Nancy Williams, to establish an annual lecture series entitled "Wally Patching Memorial Lecture" passed unanimously and was raised in relation to the 2005 AGM.

NEW ACTION ITEM: to invite speaker(s) for the 2005 AGM.

NEW ACTION ITEM: Dianne to suggest at next Ottawa chapter TFC meeting (May 11th) that the Thry'vors AGM piggy-back with a 2005 TFC meeting in Ottawa.

NEW ACTION ITEM: To incorporate a Thry'vors lecture (i.e. The Wally Patching Memorial Lecture) into the day's events, next year in partnership with or in conjunction with TFC conference series of lectures.

NEW ACTION ITEM: Lorilea, Louise and Dianne to form the planning committee and to meet to finalize venue (Ottawa or near there), date (May 14th, 2005 tbc), theme ("Not a walk in the park" tbc), etc.

4. New item: Crisis Intervention

Rita introduced a new item to the agenda. A suicidal email message, written in French, was retrieved on April 9th, 2004 from the thryvors@sympatico.ca account. The actions taken by dedicated and concerned Thry'vors members were discussed in detail and several recommendations were put forth as Action Items in order to responsibly deal with similar situations in the future. Great attention was given to establishing parameters within which members and listserv moderators might respond to such messages and postings.

NEW ACTION ITEM: Patricia to establish protocol, working with Dr. Rodin, to be followed by support volunteers when a crisis situation is suspected.

The following resources will be gathered and provided to Patricia Sharkey to consider making use of as she puts together a protocol for crisis intervention:

NEW ACTION ITEM: Jodi to find Quebecois crisis resource to include as a link or telephone number for French-speaking visitors to the website.

NEW ACTION ITEM: Grace to contact Cancer Connection for French resources (QRCC).

NEW ACTION ITEM: Grace to forward contact information for Mary Vachon to Patricia.

5. Strategic Plan

Rita thanked Nancy for her hard work in setting out a draft outline of the Thry'vors Strategic Plan. An important advance was made in the organization of Thry'vors after revisiting the by-laws last year: the identification of a need to create a Strategic Plan for the organization. Nancy drew the group's attention to the circulated copy of the Draft Strategic Plan (Outline) 2004. In it were identified the Mission, Vision, Values, Goals, Objectives, Initiatives & Committees, Role of the Board, and Format to be used. It was highlighted that among the values, respect and personal reward were very important. Rita emphasized the importance of having the Strategic Plan on paper so it may lend structure to the group.

NEW ACTION ITEM: The executive would meet to fill in the blanks of the objectives as outlined in the draft of the 2004 Strategic Plan, and present it to the board.

6. Other business

With no further business, Rita adjourned the 2004 Annual Business Meeting at 2:30 pm.