



***The Canadian Addison Society
La Société Canadienne d'Addison***

***2 Palace Arch Drive
Etobicoke ON M9A 2S1
1-888-550-5582***

E-Mail: admin@addisonsociety.ca

**Minutes of the Annual General Meeting
Saturday, October 13, 2018
Woodstock, Ontario**

The Canadian Addison Society Annual General Meeting was held Saturday, October 13, 2018 at College Avenue Church, 22 Wilson Street, Woodstock Ontario. Approximately 40 members were in attendance.

The Annual General Meeting was called to order at 1:00 pm Eastern Daylight Time by Rick Burpee, Secretary-Treasurer.

Adoption of Minutes from the 2017 Annual General Meeting

The Minutes of the 2017 AGM were published in the Fall 2017 Newsletter.

The motion to accept the minutes was duly nominated, seconded and approved by a show of hands.

Financial Report

The yearend Financial Report (attached) had been included in the Notice of Meeting. Rick Burpee, Secretary-Treasurer, updated the numbers to September 30, 2018.

Net income for 2017 was \$5824, an increase of \$3482 over 2016 as a result of slightly increased revenue and reduced costs. The reduction in costs is from less work in the Pfizer sponsored work program and only three newsletters issued (versus four in 2016). Donations continued to represent roughly 70% of revenue in 2017.

Year to date in 2018, net income is -\$1232, resulting in cash on hand of \$69,000. Donations are down as are membership fees. Membership fees are down from 2016 reflecting the first full year of no renewal requirement (lifetime membership). Since the last AGM, 60 new memberships have been issued bringing the total number of members to 250.

The bulk of donations are received in memoriam. 2017 was an exceptional year with total donations exceeding \$8000. Year to date, we have received \$3800 in donations.

However, we are in the process of receiving a donation of shares of Brookfield Asset Management from the estate of Donald Frederick Morgan. These shares have a value of approximately \$7500 (as October 9, 2018).

PRESIDENT'S MESSAGE

To all Directors, Officers, Members and Guests
It has been a good year for the Society.

Of course, being a volunteer organization there is always a need for more volunteer hours to accomplish more of the things we believe to be important to members. Regardless of this perpetual "person-power" shortage, we should all be extremely proud of the Society's accomplishments this year.

As you know, the Society has many priorities including for example these Support Group Meetings. But possibly even before these meetings we might consider number one being our individual survival from adrenal crisis. To support this priority initiative, we focus on a few major elements:

1) Everyone needs an emergency injection kit

We continue to assist members who have not yet been able to convince their doctors on the need for an Emergency Kit and what the contents of those kits should be. One way we do so is by drawing their attention to the Society's brochure.

2) Everyone needs to know how to self-inject in case of a suspected adrenal crisis.

Training is a must at every support group meeting across Canada

3) Family and friends need to know how to inject for you in case of suspected adrenal crisis

Teach them or bring them to a meeting if possible.
Practice, practice, practice, is a strategy for survival.
Don't mess around with this, it is deadly serious.

4) Paramedics need provincial approval to inject in case of suspected adrenal crisis

At the urging of the Society, among other advocates, on July 17 last year the province of Ontario implemented the first-in-Canada province wide paramedic protocol for "suspected adrenal crisis" and the assist and/or inject of a patient's emergency Solu-Cortef (hydrocortisone). We have member feedback on how they experienced this assistance and what a relief it was to have paramedics taking care of the injection in a crisis.

At that time elsewhere in Canada, Nova Scotia and Newfoundland and Labrador had "Special Patient Programs" in place where they would assist and/or inject for patients that previously had been registered with their Paramedic Service. In the Territories,

Paramedic Service are not always the same although the protocol is under review in some areas. In others, Community Nurses managing Health Centres can in some cases, administer hydrocortisone for suspected adrenal crisis. Most other parts of Canada are now working toward some form of a protocol.

As of late September, we are pleased to advise that NL have announced a new province wide protocol for adrenal crisis AND they will carry Solu-Cortef (hydrocortisone) on all 179 Ambulances in the province, another first in Canada and achievement of our goal. *NL now takes over from Ontario as our template for the nation.*

To continue the chain of necessary survival strategies going forward we need to continue our efforts by addressing the following:

5) As Paramedic approval is achieved in each jurisdiction we need to then pursue the Education system to protect our Adrenal Insufficient children while in the care of educators. Student Medical Plans do often exist in some regions, for several medical conditions, but it will be rare to find AI represented. This needs our attention. Parents of children with AI already know this only too well.

6) Emergency Room physicians and Nurses need to know that an emergency injection or IV of hydrocortisone is urgently required. We have been in touch with the Canadian Association of Emergency Physicians promoting this objective and advocating for Emergency Physician training.

7) Hospitalists and Nurses need to know that you may need an emergency injection in case of suspected adrenal crisis when an in-hospital patient. Doctors orders for same need to be on your chart in your hospital medical unit or it won't happen. Don't assume.

8) Medical Schools need to better understand the need for more emphasis on this matter in their Physician training

9) Colleges and Universities training Nurses need to better understand the need for more emphasis on this matter

This is our check-off list for our survival initiative. Each is essential, and all follow the obvious chain of events from Paramedic pickup to that of hospital in-patient status. Some objectives are needed for today's crisis and some are looking forward toward a better awareness and understanding by the medical community. Other Society initiative items that have happened, are occurring or under consideration for the near future include the following:

1) Surgical Guidelines –

– have you seen it? --have you given a copy to your Endo, your GP, your Surgeon, your Dentist?

2) Our website is undergoing yet another behind-the-scene rebuild to insure we stay current and can add newer features to the site. We recently added the video "Into the Light". In addition, we are planning our YOUTUBE channel and our first entry will be the ICE-COLD MOM episode of Untold Stories of the ER featuring the scary story of our own Shannon Meister's ER experience and Addison's diagnosis.

3) As mentioned last year, our webmaster, Jeff Wilson, had added a translation feature offering a French translation for many of the documents on the website but it cannot translate PDF's... he believes he may have that mystery resolved which would allow virtually everything on the site to be translated to French directly from the website. More news to follow.

4) Our Brochure Holder program is now a national program as featured in the last Newsletter. Member volunteer Melanie Westover has taken charge of this national program. It is supposed to be on the website by now but got caught up in the current rebuild. It will appear soon.

5) On our list for the future is a new *injection instruction sheet*. I would also like to see us develop a version that may be folded small enough to be included in your emergency kits.

6) To compliment this, we hope to eventually develop a new injection training video. However, the new injection instruction sheet comes first as it will also play the role of a storyboard for the shooting of the video. So, first things first.

7) There are of course other achievements as well as other ideas for the future. There is no end to the opportunities for the Society to consider.

The greatest challenge remains that of finding volunteers qualified, willing and able to tackle some of the grunt work involved in turning these objectives into reality while following the Society's plan.

Speaking of volunteers, my most sincere thanks to the members of the Board of Directors and fellow Officers for their ongoing support and to you the Society's members for your confidence. Our significant rise in membership numbers over the last year (almost double) suggests we are doing some things correctly and the need continues.

Special thanks to Rick Burpee our Secretary/Treasurer for all the important and unseen work he does for us every day.

Special and Honourary mention and thanks must go from all of us to member Gino Innamorato, our volunteer Researcher.Educator. Gino has invested so much personal time on the National EMS Initiative. I would not be able to even guess at the hours, days, weeks. months he has contributed in trying to make this happen on a national basis with nine provinces and three territories. We all owe him a huge thank you as his efforts save lives.

Special mention and thanks also go to Director Gerry Ott who has played a similar role in BC and after years of effort appears to have hit pay-dirt for BC members. Training of Paramedics is either planned or underway waiting for the legislative changes to be put in place before actual implementation may occur.

As I said at the beginning, what could be more important to ourselves and our families than our survival. The efforts of the many volunteers in all Regions are part of that, whether it is the Regional Representatives or others that help at Support Group meetings, or other responsibilities, it is all necessary or things just wouldn't happen.

With a number of these documented initiatives achieved and/or planned, someone needs to take over leading the Society effort forward, from an overview and leadership perspective. I speak of course of the role of the President and General Manager. At the 2019 AGM we will need someone willing and capable of leading the organization forward, and not into a ditch. Know that the Society is playing a very important role for all of us plus those who are yet to be diagnosed.

I have learned so much more about my disease by being involved with the Society. Knowledge that has helped me cope with it for the last 16 1/2 years. I started with the Society volunteering to help at meetings, then agreed to be the Regional Rep, then both Rep and a Director on the Board, then Regional Rep, Director, as well as President and General Manager.

It has been a great way to learn of the Society's structure, how it functions and learn more of the disease. All of this helped as I moved forward into my current volunteer position as Director, President and General Manager. A few in the Society are well along a similar tract and they need to consider the next step. Others should consider starting on this rewarding journey.

Thank You
Harold Smith, President

Election of Directors and Officers

The Notice of Meeting indicated one Director position was up for election for a one-year term. No nominations were submitted prior to the meeting. During the meeting, Harold Smith was nominated for the position and agreed to accept the nomination with the understanding this will be his final year as a Director as well as President of the Society. The nomination was moved, seconded, and approved by a show of hands.

Officers: President – Harold Smith (1 year)
 Vice – President – Derek Burpee (1 years)

Directors: Harold Smith (1 year)
 Derek Burpee (1 year)
 Derek Clarke (2 years)
 Gerry Ott (1 year)
 Elizabeth Hill (2 years)
 Heather Raczynski (2 years)
 Roger Steinmann (1 year)
 Holly McLean (2 years)
 Nancy Bingeman (2 years)

Rick Burpee remains as Secretary-Treasurer to complete the suite of Officers

Update to Bylaw #1

The Notice of Meeting included proposed revisions to the Bylaws to bring it up to date reflecting lifetime membership (versus annual) and to keep termination options consistent with Canada Revenue Agency requirements.

After being duly moved and seconded, it was approved by a show of hands. The approved bylaw is attached to these minutes.

New Business

Member Danielle Thede addressed the membership with some of the initiatives she felt the Canadian Addison Society should be addressing. There was some general interest expressed about members volunteering to work on initiatives along with President Harold Smith, in part to get a better understanding of the President's role with the aim of developing a pool of members interested in taking on roles within the executive and Board of the Society, up to and including the President's role.

Meeting Termination

The meeting was terminated at 2:00 EDT.