



The Alliance

The newsletter of the Canadian Immunodeficiencies Patient Organization.

Quebec AGM a roaring success



Turnout for the Quebec Annual General Meeting of CIPO was staggering, considering the population of Quebec City. Over 100 people attended the meeting and almost all came to the social event following

Dr. Hebert hosted the meeting and there were speakers on all the IgIV products available in Canada, as well as those awaiting license approvals. Baxter, Bayer, and ZLB Behring made presentations.

Dr. Pierre Boivert spoke on the prevention and treatment of sinus infections, and this was followed up with a talk from Mr. François Laroche from the Quebec Chapter of the Canadian Hemophilia Society. He explained how their chapter has evolved and has worked to improve care of patients with Hemophilia in Quebec.

A fair number of nurses also attended the event, with a good group of them coming from Montreal.

Mr. Laroche's talk was followed with discussion amongst all about formaliz-

ing the CIPO Quebec Chapter and by the end of the meeting a chapter meeting was set up. That meeting resulted in a full board for the Quebec Chapter, which will be incorporated in the first 6 months of 2006.

The social event was by far the best one to date. Dinner was aboard the cruise boat the Louis Jolliet, which left from the Chouinard Pier at 7 p.m. and returned at 11 p.m. A buffet dinner (the Roast Beef was amazing) was served followed by dancing and socializing. All who attended enjoyed the event immensely.

Elections were held at the Quebec City meeting, and we are pleased to announce the following additions to the board:

MICHAEL WHELAN
Secretary, BC Chapter President

JACQUES DAGNAULT
Quebec Chapter President

CHARLES L'ÉCUYER
Young Adult Representative

A full listing of the Board of Directors for CIPO can be found on page six.

“Comprehensive Care” Conference in Toronto

CIPO, along with a number of other organizations that represent patients with rare blood disorders hosted a conference on Comprehensive Care in Toronto, February 3-5, 2006. The conference was possible because of sponsorship by ZLB Behring, Bayer, Baxter, Canadian Blood Services, Hema Quebec, as well as a grant from Health Canada.

Many international speakers in areas of primary immune deficiency, hereditary angioedema and other disorders spoke on both comprehensive care models and existing patient registries. >> p 2

THIS ISSUE:

Quebec AGM p1

“Comprehensive Care” conference in Toronto p1

Events Calendar p2

CBS Meeting Update p3

In The News p4

Profile: Young Adult Representative elected p5

Two Fellowships programs p5

CIPO board member goes to IDF in Florida p6

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Comprehensive Care cont'd



> Dr. Carrock Sewell from the U.K. spoke about comprehensive care for primary immune deficient patients in the UK, and about the U.K. physician network PIN for "Primary Immune


Network." He also touched briefly on the UK patient registry.

Dr. Hans Ochs, Professor of Pediatrics at the University of Washington spoke

about the U.S. patient registry and how that moving forward it will be compatible with the UK registry. He is working closely with Canadian doctors that are hoping to create a Canadian version of the same database.

Anne Gardulf, from Stockholm, Sweden spoke about self-care and the studies she has overseen in Sweden. She has authored a number of articles on the cost, safety and effectiveness of subcutaneous infusion of gammaglobulin. She also spoke about her study on patient quality of life, and how this form of treatment has resulted in patients reporting increased quality of life in almost all areas.

Local speakers include Dr. Robert Schellenberg, an immunologist treating adult primary immune deficient patients in B.C. He spoke about a home care model for primary immune deficient patients in British Columbia. Dr. Bruce Ritchie, a hematologist in Edmonton also spoke on his proposal for a comprehensive care clinic to include patients with a number of rare blood disorders in Alberta, and how this will include self-care for PiD patients.

Turn out for the conference was very high and everyone that attended felt the benefit of meeting for the two days provided an incredible opportunity to share ideas and form networks which will continue in the future. 

Events Calendar:

* Contact CIPO for more information on any of the listed events

Blood Donor Day at the Rogers Centre with the Toronto Jays

June 14th, 2006.

Sponsored by Canadian Blood Services.

If you are a recipient of blood products and live in Ontario or will be in Toronto on that date and would like to attend, call CIPO at 1-877-262-2476 and two tickets will be made available to you free of charge.

Winnipeg Regional Patient Conference

June 17th, 2006

Venue – Auditorium (Room RR227), 2nd Floor, Rehab Hospital
800 Sherbrooke St., Winnipeg, Manitoba

Program Highlights: Presentations on all IgIV products presently available in Canada, also talk on prevention and treatment of sinus infection. Formalization of Manitoba Chapter. Speakers on PiD include Dr. Carrock Sewell – UK, Dr. Elie Haddad-Montreal, and Dr. Richard Warrington, who will also host.

Social dinner Saturday evening off site.


Edmonton AGM Conference

August 5th, 2006

Venue: FantasyLand Hotel, Edmonton, Alberta

Program Highlights: Presentations on all IgIV products presently available in Canada. Formalization of Alberta Chapter. Featured speaker: Dr. Hans Hans Ochs, Professor Pediatrics, University of Washington. Dr. Bruce Ritchie will discuss comprehensive care/self care proposal for Alberta for Rare Blood Disorders (PiD included) and will also host the event.

To register for any of these Meetings, or get info.
contact CIPO at 1-877-262-2476



WANTED
 Young Adults age 16 -
 25 living with Primary
 Immune Deficiency to
 join Yahoo email Support
 Group.
 E-mail:
 tina.morgan@cipo.ca

Canadian Blood Services (CBS)

National Liaison Committee Meeting updates *By Michael Whelan*

Monday June 6, 2005

The meeting was co chaired by Adelaide La Plante and James Kreppner two members of the CBS board who take back the consensus and opinions of the Liaison Committee.

The CBS is a relatively new organization and they wanted an outsiders opinion of results to date. National Board contracted with a consulting company to review and evaluate the structure of the CBS organization. The report said that CBS was one of the best organizations they have ever reviewed. The special notes said that the Balanced score card approach clearly identified all areas that will be a focus. They also recommended the same format for the seven National Community Liaison Committees.

The review commended the open and transparent nature of the CBS by putting in place something not seen in a group of this type, the National Liaison Committees, and asking for their input on board issues.

We did get some information on the national CBS suggested prescribing of IVIG and how each province prioritized and how they optimized the use of IVIG. Each province has established different systems. B.C. uses a 4-point system. C-1 is chronic care C-4 is one time use. In B.C. approval for the chronic use of IVIG by a patient is put in the hands of specific doctors. CBS is working on a first draft of IVIG clinical practices. It will be completed by the end of June 2005 and the final draft is expected to be complete by the end of the year. An immunology panel will complete a paper by March '06. Watch <http://transfusionmedicine.ca> for further updates.

According to CBS's budget, IVIG represents 35 % of the national budget or \$140 million. This is the biggest share of the budget.

National Strategic Issues. The two sided donor paper questionnaire is currently in use is very difficult for donors to follow and difficult for staff to proof read. A touch screen questionnaire is being fast tracked. The intent of this new process is to create a form that will have fewer errors and easier for donors to update their donor information and will replace the paper process currently being used.

Other on going, key indicators and emerging Strategic issues:

- Emerging threats. (e.g epidemics or new virus)
- Reactions
- Rejections
- Supply vs. demand

Heather Hume talked about emerging optimal utilization of blood components. She said that CBS is using **new technologies** to process donor blood. The new technologies do a much better job processing the blood, which means that there is now a surplus of some components and it extends the shelf life of other products. Surplus protein will be sold to countries in need. A benefit of the extended shelf life is that it reduces the cost of products to patients.

October 24 – 25 meeting in Ottawa

Day one was focused on reports and presentations and the day two agenda was built around a face-to-face stakeholders and Canadian Blood Services Board of Directors meeting Monday Night all NLC and Board members attended an evening celebrating 60 years of saving lives. This gala event honours those organizations and individuals who give selflessly of their time energy and yes, their blood and bone marrow

to save countless lives in Canada.

Back to the meetings....The day started with the announcement that Gordon Sanford, Aplastic Anaemia and Myelodysplasia Affiliate, is a new Co chair of the NLC, and board member of CBS.

The board of directors has amended the Sponsorship/Corporate Solicitations Policy to exclude those in conflict with Canadian Blood Services objectives. In other words they must be complimentary to CBS Mission.

The CBS commissioned an evaluation of the NLC and the following changes have been authorized; Maintain current size of 25 members and current balance of health care professionals, regional liaison committee and blood products user groups. In order to do this there will be some mergers of Community Liaison Committees and rename them as Regional Liaison Committees as they will cover larger geographic areas.

There was a lot of discussion about who or what organizations were at the table ensuring that "all the right people are at the table or represented". This was not an easy topic and will probably be an ongoing discussion.

Member groups are appointed to a three-year term. They will be sent letters to see if they wish to continue past the three-year term or holiday for a rotation.

There was a presentation by each of the Regional Liaison committee Reps. Most focused on building the youth component of the donor program, newer ones commented on their structural development.

We had presentations on West Nile Virus and CBS Pandemic Planning by Dr. Margaret Feron. The plan focused on how the CBS will be able to main- >>

CBS cont'd


> tain the blood supply when, not if, the pandemic strikes.

Dr. Sue Smith and Mathias Haun made a presentation on plasma protein products strategy. Recent developments included the notice that Talecris will be establishing a Canadian Division of Bayer and will be labeling the Canadian IVIG product as IVIGnex. With these changes imminent CBS will reassign their contract to the new company and hold back on the RFP until 2006 or 2007.

Ian Mumford reviewed the balanced scorecard results and discussed the future objectives of the CBS.

In the afternoon of day One Dr. Mindy Goldman treated us to a lively discussion and review of the updated Blood Component Recalls/Notification recall manual. This was very interesting in light of the long discussion at the June NLC June regarding the Hamilton withdrawal. As usual questions were asked and clarifications given on points that were unclear to us non medical folks.

Last but not least CIPO had the opportunity to explain the fact that in Canada hospital based IVIG is the norm. What CIPO wants is the CBS board to include Sub Q products on their next RFP and to support CIPO in their efforts to have immune patients included in all national pandemic planning. This means support for alternate delivery programs such as a home based IV and a Sub Q program Canada wide. We also made the board aware of our desire for comprehensive care clinics for all Immune Deficient Patients.

The Board expressed support for CIPO's efforts to get sub Q and are committed to RFP any Health Canada approved Sub Q product. To further their knowledge Dr. Sue Smith, Executive Director, Plasma Products and Services, will work with CIPO to gather and expand CBS knowledge of this product and system. 

In The News



Adverse drug reaction database goes online

In May of this year, Health Canada made its database of adverse drug reactions available to Canadians in a searchable online format.



Anyone with internet access can research side effects of drugs as recorded in the

Canadian Adverse Drug Reaction Information System, which is managed by Health Canada's Adverse Drug Reaction Monitoring Program (CADRMP)

Those interested should go to the site at http://www.hc-sc.gc.ca/dhp-mps/medeff/advers-react-neg/fs-if/cadris-2_e.html. A link to this site is also available on the CIPO web site, on our links page.

Hand sanitizer keeps bugs away

Using the now widely available alcohol based hand cleaning gels cuts the chances of picking up a bug, according to a study from Children's Hospital Boston.

The article summarizing the study was published in the September 2004 issue of "Pediatrics." The hospital's infectious disease division recruited 292 families (with at least one child in daycare) for the study.

The study showed a 59% reduction in the spread of gastrointestinal

illnesses from children outside home daycare among families that used the gels. It also showed a 20 percent less likelihood of getting respiratory illnesses.

This is good news during flu season, as contrary to popular belief, the main gate of transmission is by contact with surfaces that have been contaminated.

Fight infections without antibiotics?

Using germs to fight germs may be the future in treating infection. At least two new methods of fighting infection are being studied in hopes of use in the near future.

One method uses a deadly enzyme made by viruses called bacteriophages that precisely execute bacteria. This method is being used in Russia with great success and is being explored in the U.S for wider use.

Another method uses compounds made by one bacterium (auto-inducing peptide). These peptides regulate behaviour in bacteria and hold the bacteria in check just long enough to give the immune system time to get there and destroy it.

Both methods offer hope of containing the every expanding problem of super bugs, but once commercially available it is unknown if they will be safe for use in those with primary immune deficiency.

Young Adult Representative elected to CIPO board at Quebec AGM

Charles L'Écuyer is a new member of CIPO's national Board of Directors. He accepted the position as the Young Adults Representative while at our AGM in Quebec City. Part of his duties in this position will require him to speak for Young Adults both in national, and international forums. He will also have input into projects and initiatives, which he thinks, will benefit young adults in Canada.

Charles was also elected to the position of Vice-President for the Quebec Chapter.

Charles is 22 years old, born and raised in Quebec City and grew up there. He lived in Vancouver for 5 months in 2003, and that is why he speaks English fluently. He has had a primary immune disorder

from birth. Both he and his brother Pierre Alexandre L'Écuyer, 17 years old were born with Bruton's Disease, also known as Aggamaglobulinemia.

He is studying economy and politics at the University Laval, in Quebec, and works part-time in a restaurant as a waiter and sometimes as a cook.

"The first 2 years of my existence I was really sick and doctors didn't know what I had. They finally found my problem and since then I got treatments every month. I live a normal life; my only big frustration is that I can't travel for a long time. But it's not that bad. I think the most important thing for us it to be in great shape, because if we are, then we are not as likely to catch illnesses", said Charles.

Charles is looking forward to connecting with Young Adults all over Canada ages 16 to 25, and will be setting up an email community so they can all keep in touch.

He is already part of an international group of young adults that have primary immune disorders, and will bring back ideas and information from around the world for the benefit of young adult patients in Canada.

To get in touch with Charles, just email him at CIPO at charles.lecuyer@cipo.ca.



Profile

A

By-The-Way

Did you know you can direct your United Way payroll deductions specifically to CIPO? Call us at 1-877-262-2476 to learn more.

Two Fellowships Programs hope to interest doctors in immunology


Bayer HealthCare, Biological Products Division (Canada) commits to aiding the advancement of physician and scientific knowledge about IGIV through the support of clinician and research fellowships. The following are two examples of fellowship programs supported by Bayer HealthCare.

The Canadian Immunodeficiency Society Bayer Fellow Exchange Program provides financial aid to trainees in Canadian fellowship programs who wish to expand their education in Immunodeficiency Disorders. As part of

this program, Canadian clinicians are able to participate in a rotation at the Hospital for Sick Children in Toronto or the Montreal Children's Hospital. Through this program there is intensive training in Immunology. By increasing awareness about Primary Immune Deficiencies, clinicians will be better equipped to identify Immunodeficiency Disorders earlier in patients.

The Canadian Allergy, Asthma and Immunology Foundation/ Bayer/CHIR-Rx&D Fellowship is another example of Bayer HealthCare's commitment to ongoing education. This program is research focused in the fields of Immunodeficiency and Novel Immune Therapies. The goal of the program is

to encourage clinicians to train as scientists in the field of Immunology. It is hoped that these individuals will stay in Canada after their training and contribute to future care and research in Allergy and Clinical Immunology

"Study in the area of Immunology is vitally important, and fellowships like the ones Bayer HealthCare supports will help expand the understanding of the disease area, and will also help with the diagnosis for patients," says Dr. Z. Chad, Associate Professor of Paediatrics, University of Ottawa and Past Chair, CAAIF. "As we continue to learn more about Immunodeficiency disorders we will be able to provide better treatment options to patients across Canada." 

CIPO Board member goes to Immune Deficiency National Conference in Florida

By Suzanne Turgeon



I was honoured to represent CIPO at the Immune Deficiency Foundation (IDF) National Conference held in Orlando, Florida on June 23,24,25, 2005. Approximately 1400 people attended.



Suzanne Turgeon (left) with Carol Anne Demaret (mother of David Vetter).

IDF was started 25 years ago by Marcia Boyle and her husband John following the diagnosis of primary immune deficiency (PiD) of her son John Jr.

Like CIPO, IDF began as a grassroots movement in Marcia's kitchen and grew from there.

They currently have approximately 10 employees and the head office is near Baltimore, Maryland. Marcia stills runs the IDF organization, which has a very strong voice in the US and is very vocal in the political arena in Washington, DC. Marcia presided at the conference, and her husband and son were also in attendance.

Several speakers were invited. Dr Rebecca Buckley, leading worldwide expert from Duke University for severe combined immune deficiency (SCID) patients (an invited speaker at some of our conferences) was a speaker and she is also a member of the Board of Trustees of IDF.

The themes of the conference revolved

around EDUCATION, ADVOCACY and RESEARCH. One of the speakers mentioned that it has been proven that it takes 9.2 years for someone to be diagnosed with PiD in the USA.

In Canada, our research shows very similar results (about 10 years). Too many people still die in 2006 without ever being properly diagnosed, especially children with SCID. How can people suffer with repetitive pneumonias for years, (even family members of nurses and doctors) without ever having their immune system checked?

IDF is working tirelessly with Washington to pass a law to test each newborn in the USA for immune disorder. It will cost approximately an additional \$44 US to get the results analyzed by a special lab. A lot of progress in terms of research has been made, especially in the last few years in the treatment of PiD.

On a more personal note, since my niece Lilia Turgeon (4 years old) suffers from SCID, the highlight of my visit was to meet Carol Ann Demaret, mother of David Vetter . David is better known as the bubble boy. He suffered from SCID and died at the age of 13 in 1984. He spent most of his life in a plastic bubble that was made at one point by NASA. David was one of the first SCID patients to live that long and continues to be a source of inspiration for patients and families affected with that terrible disease. Ms Demaret who is also a member of the Board of IDF gave a very emotional speech. The conference was dedicated to her son.

This was the 3rd IDF national conference. So far they are being held every 2 years. I am really glad I had the opportunity to attend and gain new information regarding PiD and made contacts with some of the speakers and attendees. We also had a special night of celebration at Disney World on our last day with spec-

tacular fireworks at closing to add to my long list of memorable moments of this very special gathering where every-one had one cause in common.

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