

CBS National Liaison Committee Meeting, Sept, 2002



< Three Musketeers Left to right Libby Tough (CIPO Treasurer), Tina Morgan (CIPO President) and Mary Carle (CIPOVP), Board meeting (part of annual meeting)

By Libby Tough

I had the great pleasure to represent CIPO at the Canadian Blood Services National Liaison Committee Meeting in September 2002. A summary of the meeting follows.

The National Liaison Committee was asked to consider if anti-core Hepatitis B testing should be added to the current tests done on donated blood, and if this testing phase should be done on one-time donations only or on those that donate a 2nd time as well?

Also, what messages should be given to the donor who tests positive on the first test when the unit is not used. Should it result in permanent deferral? We were to take into account the following issues:

1. Decrease in HBV (Hepatitis B) transmission,
2. Donor loss,
3. Potential effects on manufactured plasma,
4. Logistics
5. Cost.

After much discussion, the NLC participants are in support of anti-core testing but require additional information to provide more definitive recommendations.

Dr. Heather Hume presented a summary to the NLC on cross-over of directed donations. Cross over means that when someone donates blood for their own use or a specific use and it is not or can not be used, that it be considered for donation to the general blood bank. The presentation also indicated that directed donations are as safe as blood from directed donors; and if they weren't as safe they would not be used.

Cross over donations would result in 300 to 600 additional units per year. Donors who are directing their donation should be advised that if they are not compatible, their donation could be used for someone else.

Consent forms will have to explain this thoroughly. The NLC raised many concerns and a presentation was made to the CBS Board Members for further evaluation. The NLC recommended that with informed consent, CBS could cross over directed donations; however hospital workload and computer systems may not support such an activity.

NLC also received a presentation on West Nile Virus (WNV). Presentation highlights included an introduction on the origins of WNV and its spread to North America. Symptoms are most severe in those with compromised immune systems, most people infected


with WNV are asymptomatic (no symptoms). Antibody screening tests are performed and if antibodies are found, chances are most probable that these cases become confirmed cases. During the screening process of donors, emphasis is placed on donors' current state of health and if the donor is not feeling well post-donation, they are always advised to contact CBS. I specifically requested more information concerning the fractionation process of IVIG and WNV. Although there have been no published reports concerning this, WNV is one of a class of viruses that are inactivated by current viral inactivation methods. Dr. Heather Hume expects that fractionation product manufacturers are busy working away at this and we will soon have published literature on the topic.

CIPO did receive documentation from Baxter in November regarding a verification study which confirmed that WNV was inactivated during their fractionation process.

As quoted from their press release "This study, using an infectivity assay with a 1999 New York isolate of the virus, confirmed that WNV was readily inactivated through pasteurization, vapour heating and solvent detergent methods that Baxter employs in the processing of its commercially available plasma derivatives." CIPO expects other fractionators will release similar studies before the start of the next West Nile season.

There was also a dinner honoring donors held in the evening. It was quite impressive and needless to say, a >>

> tear-jerker. I am glad that I attended this meeting and will continue to keep you informed of new issues concerning CIPO patients and the Canadian Blood Services in the future.

For more information regarding the National Liaison Committee, we recommend that you take a look at the Canadian Blood Services website. This site can be reached via the CIPO web site (under patient links, clicking on CBS, then Public participation, and then select the NLC link) or by going to http://www.bloodservices.ca/centreaps/internet/uw_v502_mainengine.nsf/web/C54E64BD15D30FCA85256B43005C138B?OpenDocument. 



Blood Safety Committee hosts post Krever Meeting

In November of 2002 a blood forum meeting was held in Toronto to review progress made since the Krever inquiry.


It was a sombre event, made more so by the fact that criminal charges were laid the day before the meeting, against doctors involved with transmission of HIV and Hepatitis C to users of blood products in the 1980's.

Participants seemed more intent than usual, and for the most part it came home to all of us just how little has been accomplished since the Krever inquiry.

The most poignant fact that came out of

the forum was that we are no further ahead in terms of tracking blood products than we were 10 years ago for the majority of patients using blood products.

This is a big issue, and one that CIPO is working hard at remedying for PiD patients. A new registry is being created, and one of the things we are looking at is tracking and recording of blood products to our patients via this software.

West Nile has also become a virus of concern. We have been ensured that the virus is inactivated in IgIV by virtue of the fractionation process, and if there any concerns in this area we will be sure to communicate this to our members immediately. 

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CIPO ANNUAL MEETING PRE-REGISTRATION FORM Halifax, Nova-Scotia, September 27, 2003, 9am-5pm.

Register via e-mail (info@cipo.net), via our website: <http://www.cipo.net>; call toll free 1-877-262-CIPO (2476), or fax to (705) 369-1386

Please tick all that apply to you:

I/We will be attending the annual CIPO Meeting

Number of attendees in your group _____

___ I/We will need ___ hotel rooms for:

___ Friday, September 26th, 2003

___ Saturday, September 27th, 2003

___ I/We will attend the dinner Saturday, September 27th, 2003:

tickets _____

Name _____

Address _____

Phone # _____

Type of PiD _____ (to help line up speakers)

Indicate whether you use IgIV _____ (Yes or No)

**all information supplied to CIPO is confidential and will not be shared with anyone!*



The Alliance

The newsletter of the Canadian Immunodeficiencies Patient Organization.

ESID Bi-Annual Meeting Weimar, Germany October 17-20, 2002



Left to right, Tina Morgan, CIPO President, Francis Rembert-IRIS Chair, Tom Bowen-CIPO MSAC Chair, Avalon Bowen

This meeting was the most exciting yet, with the emergence of a number of successful genetic treatments for x linked forms of SCIDs. Immunologists that are involved in trials in this area were at the meeting and the main message was that there will be more patients in these trials over the next few years, and that present indications show they are as successful as bone marrow transplants and may perhaps turn out to be better.

Europe is well ahead of North America in terms of treatments options. Sweden has been offering subcutaneous infusions for many years now, and companies selling pumps and equipment were at the meeting.

The pumps being sold in Europe are small and quiet. One was not much bigger than a pager. The next generation of needles for subcutaneous infusion were amazing. One system had an angled needle and breathable bandage as one unit, so they cannot be inserted incorrectly. The pumps are

programmable and cannot restart automatically if there is a blockage, making them safer. The pumps were not cheap; with the better ones in the \$2,000 U.S.D. range, but were in line with costs of IV pumps in general.

All the news was not great. We heard news regarding fourteen cases of neurodegeneration in PiD patients who were regularly using IgIV. Twelve of these patients subsequently died. vCJD was ruled out during autopsy.

Since no one knows what caused these cases there was a request for other countries to actively monitor patients. As far as we know, no cases have been seen anywhere else. CIPO will be working on getting more detailed information on this issue, and will put a follow up article in our next newsletter. Also this issue will be discussed during our MSAC meeting in April. >>

Canadian Clinic Network launch to be announced

On April 25th, 2003 in Toronto, Ontario the SSBIC (Specialized Systems for Blood and Immunology Corp) will announce the launching of a Canadian Clinic Network for primary immune deficient and hereditary angioedema patients. This meeting is very important to CIPO members, as it will be another step toward home care for patients in Canada, and bring standard care to patients no matter where they live.

The main objectives of this clinic network and meeting are:

1. To create a registry for patients to collect information about the primary immunodeficient and hereditary angioedema patient populations >>

THIS ISSUE:

Weimar, Germany: Bi-annual ESID Meeting

Canadian Clininc Network launch announcement

CalgarySuccess: CIPO's Annual Conference

CBS National Liaison Committee Meeting

Blood Safety Committee host Krever Meeting

CIPO Survey: Patient Treatment

This letter generously sponsored by

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ESID Bi-Annual, Weimar cont'd



Left to right: Assorted members of French patient group IRIS, (Starting with gentleman in red tie) Fred and Vicki Modell (Jeffrey Modell Foundation), Francis Rembert-IRIS, Tina Morgan-CIPO

> There were many scientific papers presented as part of the conference, and some were quite exciting. One study looked at the expression of the SAP gene in common variable immunodeficient (CVI) patients. This gene is usually expressed in Bruton's (aka X linked Agammaglobulinemia). A few of CVI

patients did have expression of this gene.


There were also many articles on what appear to be disorders amongst CVI that many argue should be removed or at least become subsets of CVI. We will likely see new disorders being found and pulled out of

the catch all of CVI in the years to come.

The nicest surprise was that there were 7 articles on genetic treatments this year, and for anyone that wants citations for these, I will be pleased to give them to you upon request. Email info@cipo.net They can also be found on the ESID web page at <http://www.esid.org/>

Also, many countries gave reports on patient registries. Countries

reporting included: Spain, Portugal, Japan, Russia, Italy and the United States. We will be able to give a preliminary report at the next meeting in 2004 on our own registry which will launch this year.

CIPO was able to solidify a partnership with IRIS, the national patient organization in France. They have generously given us much printed material so we can ensure good literature for patients in the French language, other than newsletters. We hope to do many projects with them in the months and years to come. 


EVENTS CALENDAR:

- **CBS National Liaison Committee Meeting**
Ottawa February 2-3, 2003
- **Canadian Clinic Network Launch Meeting**,
Radisson Hotel,
Lakeshore Toronto,
Ontario April 24, 2003
- **Visiting Professor Visit McGill University**
Montreal, Quebec
*Patient gathering planned, please call/email to register.
June 16-17 2003
- **CIPO Annual Patient Meeting** Halifax, Nova Scotia September 27, 2003
- **IDF National Conference**
June 19-21, 2003
Marriott Waterfront Hotel Baltimore, Maryland Inner Harbour



CIPO President, Tina Morgan (leaning in) with the French Patient Group Board

Clinic Network launch cont'd

- > in Canada. This registry will reside under Health Canada.
- 2. Standardize care in every province in Canada for primary immunodeficient patients. Present diagnosis and treatment protocols vary across the country. This will include a discussion which will end with a consensus on standard diagnostic and therapeutic algorithms.
- 3. Lay the basic foundation for establishing home care for PID patients in Canada.
- 4. Ensure off label usage of IgIV is funnelled towards clinical trials where available.
- 5. Find synergies with Haemophilia clinics, and partner with these clinics where possible.
- 6. Discussion and implementation of hemovigilance.
- 7. Partner Canadian testing laboratories to provide services for diagnosis of PID, HAE and rare blood disorders.
- 8. Raise the clinical profile of PID, HAE, complement, and rare blood disorders for Canadian researchers and clinicians to stimulate research and development in these areas.
- 9. Hold the first annual meeting for the PID/HAE Rare blood disorder clinical network (SSBIC). 



CIPO's Annual Conference: Calgary, Alberta, July 27&28

The CIPO annual conference was held in Calgary, Alberta July 27&28 in conjunction with the Canadian Hereditary Angiodema Society. The conference was the most productive and informative we have had to date. Co-hosting this meeting worked extremely well, creating a larger understanding of just how many different variations of health care dependant people there are across the country.

There were twelve speakers, a number of different committees and board meetings and a cowboy poet!

The speakers at the conference in chronological order were Michelle Phillips (Genetic Counselor, Calgary Foothills Hospital), Dr. Tom Bowen (CIPO MSAC Chairman), Dr. Ramon Farhood (Baxter pharm.), Dr. Mark Pickett (Bayer pharm.), Dr. Bruce Ritchie (Canadian Hemophilia Society), Peggy Adomatis (Hereditary Angioedema patient), Suzanne Dietrich (Canadian Blood Services), Dr. Bob



Mary Carle talking to a patient

Schellenberg (CIPO MSAC), and Tina Morgan (CIPO President).

Gordon Colledge, an instructor in Family Studies at Lethbridge



Tina giving David Goodman the Good Samaritan Award

Community College was our key note speaker at our dinner on Saturday evening, and helped us all have a good laugh at ourselves.

David Goodman, a salesman with Baxter received our 1st Good Samaritan Award for all the help he has given CIPO over the past 5 years.

Last but not least was an evening of poetry from cowboy poet Doris Daley, for patients and doctors that stayed on until Sunday.

To say that a lot of ground was covered at

this meeting would be an understatement. Many ideas and suggestions came out of the conference and are under development.

Dr. Bowen's speech filled many patients with hope. He focused on how much doctors and patients working together can and will improve the diagnosis and treatment of patients suffering with primary immune deficiencies. He also touched on topics like genetic treatment trials going on all over the world and up and coming treatment options like home infusion and subcutaneous infusion. We look forward to his topics at our next annual meeting.

Dr. Schellenberg spoke about primary immune deficiency and also improvements made in British Columbia. He was part of a working group that established with all hospitals a minimum trough level of 700 mcg for primary immune deficient patients.



Left to right: (foreground) Avalon Bowen, Dr. Bruce Ritchie (background) Tina Morgan and Dr. Tom Bowen annual meeting



Jean Burnham announcing cowboy poet at annual meeting dinner Sunday

Both Baxter and Bayer spoke about future products that will be available for patients in the months and years to come.



Dinner for the Families at the Annual Meeting

Dr. Mark Pickett from Bayer presented a new product that will likely be launched in Canada within 2 years, and gave patients an in depth look at the new caprolite process.

Dr. Ramon Farhood from Baxter spoke in more general terms about subcutaneous infusions and the future of treatments in the industry, and provoked much discussion.

Baxter also indicated a 10% liquid formulation should be available very soon.

Rep. Suzanne Dietrich of Canadian Blood Services spoke on a number of aspects regarding blood and blood donation. The main topic was the most recent promotional campaign to raise awareness of the importance of blood donation. The jingle for the campaign is “roll up your sleeve”. There is also a

pilot program which involves a “blood mobile”, and one where CBS representatives go into schools to educate and raise awareness among young people as to the importance of blood and blood products in the health care system.

Per capita donation rates for other countries are New Zealand 5%, United Kingdom 6%, United States 6%. Canada is 3%.

We have some distance to go before we can hold our heads up in this area. As always, we tell family and friends the best way to help patients with PiDs is to donate blood as often as you can.

Patients are more grateful than words can relate to people who give this gift.

CIPO internal report-board elections were held in Calgary, Alberta July 27,



Left to right Mark Pickett, James Kovac and Jennifer Scharpf-Bayer, Mary MacSween, and Dr. Mike MacSween

2002. The results of the elections were TINA MORGAN—President, MARY CARLE— Vice President, AVRIL FREELAND—Secretary, LIBBY TOUGH—Treasurer, CHRIS MORGAN— Communications and Editor, DON TOUGH— Webmaster, DR. TOM BOWEN— CIPO MSAC Chair.



CIPO survey on patient treatment

CIPO is doing a survey on current and future treatments among Canadian patients.

This survey is being done with the sponsorship of a pharmaceutical company in Canada that is donating \$25 for each survey completed.

All funds will go toward our patient meetings in 2003 and 2004.

Survey can be completed until June 30, 2003.

Surveys are sent to CIPO only, and information, reports etc. will be drafted by CIPO and generic reports/graphs made available to any interested parties on our web site by year's end.

You can get a survey by contacting CIPO, or visiting our web site at:

<http://www.cipo.net>

and looking on our links page. Support CIPO and take part!