

The Alliance

The newsletter of the Canadian Immunodeficiencies Patient Organization.

CIPO Lindt Helping Hand Fund launched



It is with great pleasure that CIPO announces the creation of the CIPO Lindt Helping Hand Fund. Lindt & Sprungli (Canada) Inc, well known for its commitment to charitable endeavors, stepped forward and gave a donation of \$5,000 to kick-start the fund. Suzanne Turgeon (an employee at Lindt and a member of CIPO) presented CIPO's proposal for the Helping Hand Fund to the company. It should be noted that CEO Rudi Blatter and his team at Lindt devote 1% of company income to charities every year, and CIPO was thrilled they decided to give to such a needy cause.

CIPO encourages every CIPO member and their families to approach their employers for donations to build this fund, so we can help as many people as possible.

The establishment of this program was a pet project of CIPO President Tina Morgan and CIPO Secretary Suzanne Turgeon.

Ms. Morgan is a patient with Common Variable Immune Disorder, and in addition to her board work with CIPO she often works as an advocate for families where diagnosis has just occurred. She knows first hand how desperately a program offering a financial safety net for families was required.

Mrs. Turgeon, CIPO board member and employee of Lindt had a niece diagnosed with a rare form of SCID a few years ago, and has seen the impact on her brother's family because of the disorder. She witnessed how utterly helpless families feel when other events beyond their control are thrown into the mix. Her brother and his wife have been coping with the emotional roller-coaster of numerous bone marrow transplants for their daughter Lilia, life threatening infections and also having the family separated for months at a time when their daughter is hospital-

ized. Because they are farmers someone had to mind the stock, and by having only one parent stay at the hospital, they knew it would disrupt the other children's lives less. As if that wasn't bad enough, last year their house burned to the ground, and recently Lilia was diagnosed with a rare form of cancer.

"This fund was set up for the express purpose of helping families where a primary immune disorder is wreaking havoc in their lives. You cannot over estimate the impact a serious primary immune disorder can have on a family," says Morgan. "Many drugs and treatments are not covered under provincial health programs, and add to that less money coming in because parents may often have to stop working or reduce hours to take >> p 3

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This letter generously sponsored by

Baxter

GAMMAGARD® Liquid approved for use in Canada

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A new liquid IgIV from Baxter (GAMMAGARD® Liquid) has been licensed for use in Canada for patients with primary immune disorders and should be available by the end of 2007.

Gammagard SD has been licensed for use in Canada for a number of years, and is often used in patients that have problems tolerating IgIV. Gammagard SD has the lowest level of IgA antibodies available in Canada. This older product will still be available to patients with sensitivity to the IgA antibodies, but the SD product should not be confused with this new product, which although lower in IgA than many other brands of IgIV, is not as low as the current Gammagard SD product.

GAMMAGARD Liquid 10% offers improved convenience for healthcare professionals and patients. Where the older product was lyophilised and required mixing, this new product is ready-to-use, sterile and eliminates the need for reconstitution. In addition, its higher concentration, compared to the old 5%, allows for a reduction in the length of infusion, reducing the infusion volume and saving time for both patients and healthcare professionals.

According to Baxter, the safety of GAMMAGARD Liquid 10% has been demonstrated in a wide spectrum of patients with primary immunodeficiency disorders. Baxter produces the therapy using a three-step viral reduction process, a unique combination used to help ensure viral safety. GAMMAGARD Liquid 10% is free of added sugar, sodium, and preservatives. In addition, the packaging is latex-free.

“The approval of GAMMAGARD Liquid 10% provides more selection for doc-

tors in Canada prescribing IgIV, and this is very important to patients, as some patients may not tolerate one brand, but will have better luck with another”, said Tina Morgan, President, Canadian Immunodeficiencies Patient Organization. “This new product is a big step up for Baxter in terms of safety and tolerability. There is no sodium, preservatives or sucrose in the product and no latex used in the packaging. It also has a 3 step viral inactivation, which shows Baxter’s commitment to safety. I’m not saying products without three steps are not safe, but as a patient I have to say I don’t mind a bit of redundancy when it comes to safety, and I’m sure other patients feel the same way.

The approval was based on a Phase III, multicenter study of 61 patients between the ages of 6 and 72 years who were treated with 300 to 600 mg/kg every 21 to 28 days for 12 months. In this study, no validated acute serious bacterial infections occurred in any of the treated subjects.

“During the clinical trial, we found that GAMMAGARD Liquid 10% was safe and effective in the treatment of patients with primary immunodeficiency disorders,” said Joseph Church, M.D., Professor of Clinical Pediatrics, Keck School of Medicine at the University of Southern California, Head of the Division of Clinical Immunology and Allergy at Children’s Hospital Los Angeles and a lead investigator in the clinical trial. “In addition, the production of GAMMAGARD Liquid 10% incorporates a three-step viral reduction process that may improve viral safety.”





Baxter intends to launch GAMMAGARD Liquid 10% in five vial sizes (1g, 2.5g, 5g, 10g and 20g). The various vial sizes will allow for tailored dosing and help reduce waste. Healthcare institutions will also benefit from the therapy's recommended storage conditions. GAMMAGARD Liquid 10% can be stored for up to nine months at room temperature, or for up to 36 months if kept under refrigeration.

"We developed this next generation IGIV therapy in direct response to the



Jeff Bakker-Baxter, Libby Tough, and Tina Morgan. Tina was so happy about the Gammard launch that she decided to don the Baxter paper clips as earrings!

needs of patients and healthcare professionals," said Joy Amundson, president of Baxter's BioScience business. "We are proud to add this important innovation to Baxter's 50-year history and commitment to safe and effective plasma therapies.

Important Safety Information

GAMMAGARD Liquid 10% is contraindicated in patients with known anaphylactic or severe hypersensitivity responses to Immune Globulin (Human). Patients with severe selective IgA deficiency (IgA < 0.05 g/L) may develop anti-IgA antibodies that can result in a severe anaphylactic reaction. Such patients should only receive intravenous immune globulin with utmost caution and in a setting where supportive care is available for treating life-threatening reactions.

GAMMAGARD Liquid 10% is made from human plasma. Products made from human plasma may carry a risk of transmitting infectious agents, such as viruses, that can cause disease.

The potential risks and benefits of IGIV should be weighed against those of alternative therapies for all patients for whom IGIV administration is being considered.

Please visit www.baxter.com for full prescribing information.



Lindt cont'd

> care of the child. These huge financial hurdles can affect the whole family."

The CIPO Lindt Helping Hand Fund will accept requests for grants up to \$500 per family per application. Criteria are that the family must prove financial need, and send confirmation from a treating medical doctor that a primary immune disorder has been diagnosed. Families where an adult has the disorder and is unable to work are also encouraged to apply where financial need is evident.



We regret to inform you that brave little Lilia was taken from us on the wings of angels October 30, 2007 at the age of 5 years, 10 months. All of us at CIPO send our deepest condolences to the family, and will continue to give whatever support we can to the Turgeon family in their time of sorrow.



Article on classification of PiD published in JCI

An article recently published in the Journal of Clinical Immunology updates the classification of primary immune disorders. The paper was written by The International Union of Immunological Societies Primary Immunodeficiency

Diseases Classification Committee; a group which has been meeting every 2 years since 1970.

The article helps to put the many recent discoveries in both research and treatment of primary immune disorders into

a format that will help doctors to better diagnose and thus create better treatment plans for their individual patients. CIPO has added a link to this article on the CIPO web site at <http://www.cipo.ca/english/mac.htm>.



CIPO AGM EDMONTON 2006

The 2006 CIPO AGM was held in Edmonton. The conference was made possible through the generous sponsorship of CSL Behring, Talecris Biotherapeutics and Baxter Corporation.

The program started with a welcome to all present and opening remarks from the CIPO President Tina Morgan. She gave an overview of the aims and objectives of CIPO and welcoming the Alberta CIPO chapter and congratulating the organizers for their efforts to bring the conference to Alberta.

The agenda was power packed with an impressive list of international and Canadian presenters. In a break from the normal Dr. John Akabutu, Professor Emeritus, gave an impressive informative power point presentation on the Alberta Cord Blood Bank that bears his name. Cord blood is used for gene therapy in the same way that Bone marrow is used for the treatment of life threatening diseases. Canada currently buys most of its supply of cord blood on the international market. Much discussion occurred regarding which was better, public or private, so we have given more information in our "In The News" section on page 5 of this issue.

Dr. Hans Ochs, Professor of Pediatrics, University of Washington, a pioneer in the field of Primary Immune Deficiency and author of many scientific papers gave a presentation on the variants of PIDs. At this time some 130 variations of Immune Deficiency have been identified. As rare as PID is, there are some variations so rare that they have been discovered in only one family.

Dr Bruce Ritchie, University of Alberta, talked about a proposal he developed for a Comprehensive Care Clinic and has submitted it to the Province of

Alberta for funding. The proposal includes patient self-care, a registry, a full time dedicated specialty nurse and a part time social worker. As a pilot project potential patients will be required to meet specific criteria.

Dr Ritchie offered a tour of his laboratory operations at U of Alberta where we saw the laboratory where he is conducting a Canada wide long-term study on blood born pathogens. Dr. Ochs also was able to speak to the doctors in a separate event, and also attended Grand Rounds.

Dr. Robert Schellenberg, Immunologist, B.C. Pacific Lung Center gave a presentation of a B.C. proposal for a P.I.D. patient self-care program. The B.C. proposal is similar to the Alberta proposal in that it is intended that selected patients will use a self-administered Subcutaneous Immune Globulin product.

Dr. Jacques Hebert talked about the IVIG funding change in Quebec. Payment for these blood products is now at the hospital, and not with Hema Quebec budget. There are only two or three hospitals in Quebec who treat the majority of PID patients and therefore use the majority of the IVIG in the province. They will be bare the burden for more than their share of the cost, and the concern is that in order to reduce costs hospitals may refuse to treat patients who are not in their catchment area, instead referring patients to the hospital nearest to their residence. This method of costing/funding may spread to other provinces, and so is being watched carefully.

There were presentations from Talecris Biotherapeutics (formerly Bayer), Baxter and CSL Behring.

Dr Kim Fisher, PhD gave a presentation explaining all the steps in processing the 5000 frozen plasma donations. It

takes up to 180 days or six months to process the plasma into its various components including the product we know as IVIG. Currently Canada does not donate enough blood plasma to meet patient's need for IVIG.

Canadian plasma will be processed separately from other plasma and the IVIG product will be known as IVNEX. A Canadian Flag on the label will further identify the product as coming from a Canadian donor.


Ramin Farhood represented Baxter and gave us an update on their new Gammagard product. Please read the article in this issue for more information.

CSL Behring a division of CSL Behring gave a very exciting presentation on the launch of their new subcutaneous gammaglobulin product called VIVAGLOBIN. This product was recently launched in the United States and patients have reported fewer side effects and are



happy that this product can be infused at home because it is injected under the skin with a syringe. Current IVIG products licensed for use in Canada can only be administered as an Intravenous product.

Canada licensed the product in 2007, and it is being reviewed by the provinces for full funding at the same level as IgIV. Until then it is only available on a case-by-case basis.

Tina Morgan closed the meeting by thanking the presenters, and everyone who gave up their long weekend holiday and travelled great distances to attend this first ever CIPO conference in Edmonton. 

In The News



Drug to be licensed for GVHD

DOR BioPharma, Inc. is a biopharmaceutical company developing products for life-threatening side effects of cancer treatments, serious gastrointestinal diseases, and bioterrorism. One product in particular may be of use in patients requiring bone marrow transplant for severe immune disorders like SCID. DOR

BioPharma, Inc. has developed a product called orBec® (oral beclomethasone dipropionate). It is a potent, locally-acting corticosteroid being developed for the treatment of gastrointestinal Graft-versus-Host disease (GI GVHD), a common and potentially life-threatening complication of bone marrow transplantation. DOR BioPharma has recently filed a New Drug Application (NDA) with the FDA for orBec® for the treatment of GI GVHD. orBec® may also have application in treating other gastrointestinal disorders characterized by severe inflammation.

Banking your baby's blood

With more and more news on advances in stem cell research, many parents are pondering whether they should bank their baby's umbilical cord blood, and if they decide to go ahead the next question is whether they should donate to a public bank, or a private bank.

Costs for a private bank vary, but initial cost starts at \$1,000, plus \$120 per year to keep it viable. The donation is held for the donor's specific use, and at their direction.

Public banking is free, but the dona-

tion goes to where it is needed most. "Public banks are strictly for stem-cell transplantation among unrelated people", says Dr. Akabutu, Executive Director of the Alberta Cord Blood Bank, "and used in treatment of diseases such as cancer, immune disorder, metabolic problem and bone marrow failure. The public bank exists to help those individuals who need a transplant but cannot find donors.

So what does this mean for families where there is a history of a primary immune disorder. Obviously advancing research in this area may translate into saving the life of a child with a severe immune disorder, but on the other hand it may be many years in the future before such treatment would be necessary. You couldn't use cord blood from a child that develops an immune disorder to fix it, because it would likely just reoccur. However cord blood from a sibling would have a great chance of working. Parents that can afford to store it privately feel it is an insurance that could pay big dividends in the future, and the cost is a premium they have no qualms about paying. What price can you put on a cure for something like SCID.

However those that donate to the public bank also feel equally good, knowing that their donation will help someone (albeit likely no one they know). They feel that if every parent donated their child's cord blood, it would mean chances of finding a match for any child or adult (should they require it) would be greatly increased.

Ultimately, the choice is yours, but donating your children's cord blood certainly is a good idea, whether it is privately or to a public bank. Just remember if your child does show signs of an immune disorder, using their own cord blood would not be considered.





Manitoba Chapter by Susan Koley

The Manitoba Chapter is slowly getting off the ground. We had our first patient support group meeting in the fall of 2006. The group agreed that our first information session was a presentation from a physician on "What is PID".


Dr. Richard Warrington, Department of Immunology at Health Sciences Centre provided a very informational presentation in the spring of 2007. Talecris sponsored a light supper for the group, and we had a lovely informal evening getting to know one another.

On August 26th, 2007 we had our first annual Family Picnic. Fun was had by all! We had a lovely lunch followed by a bocci ball

tournament, kite flying, and some preferred to throw a Frisbee around! This event was solely sponsored by CIPO. I would like to thank Nicole Leslie for assisting with planning the picnic. I would also like to thank everyone that attended our first annual Family Picnic! Next year will be even bigger and better! A special thank you to everyone that pitched in to assist with food, games, etc.



Tina Morgan and Susan Koley at the Winnipeg meeting

Sub-Q IG Dr. C. Kalicinsky Department of Immunology, held a presentation, and some patients with vein access issues are already starting to get Sub-Q IG. 



Moments from our first annual family picnic.

International Conference on PiD Budapest, Hungary 2006

by Mike Whelan

Attending the combined IPOPI, ESIS and INGID meetings as the National Representative of CIPO was the experience of a lifetime. There were 60 delegates from 21 countries at the IPOPI sessions and a combined total of over 1,000 International representatives attended the weeklong focus of Primary Immune deficiency. Never have I been in the presence of so many professionals so dedicated and concerned about the welfare, wellbeing and treatment of Primary Immune Deficiency patients worldwide.

My thanks and appreciation to Tina Morgan for asking me to attend on Behalf of CIPO and her hard work finding the money for me to attend this prestigious conference. I would be remiss if I didn't give a big thanks to Talecris for stepping up and providing the funding on short notice.

The conference as a whole were very focused on getting IVIG re-established a critical drug on the World Health Organization (WHO) List. These was a lot of lobbying for all members to write and send petitions to WHO on their website.

Highlights of my trip

- European Doctors reported a 40% success rate with 14 gene therapy patients and are very optimistic that gene therapy success rate will improve

over the next few years and present the remedy for many more patients in the future

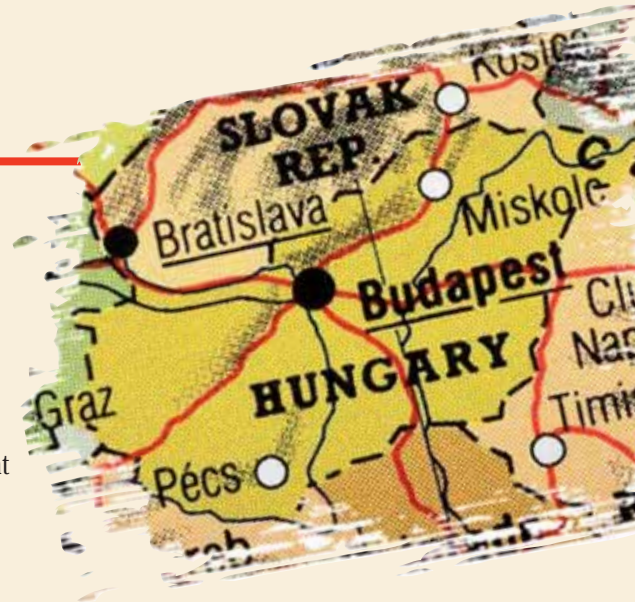
- Meeting the many member Non-Profit organizations from around the world that make up IPOPI and collectively are very strong in the support of the cause of Immune Deficient patients around the world.
- Meeting with Immune Deficiency Foundation (IDF), with Immune Deficiency Foundation of New Zealand (IDFNZ) and David Watters Executive Director of IPOPI. My goal in meeting with them was to find out how they do their fund raising, what do they spend the money on and the structure and duties of their board members; and what other organizations they collaborate with to get the message out.
- The Young Adults conference is to take place in England in 2008, and they are currently looking for funding for this conference.

The next combined IPOPI, ESID, and ENID Bi-Annual Conference will be held in Holland in 2008.

The 2006 organizing Committee expected 600 delegates and were surprised and happy to have 1000 delegates. Applications for Holland will have to be in early in case attendance is limited.

IPOPI welcomed four new countries including Australia, Hungary, Iran and Argentina to the fold. Argentina is from Buenos Aires and can be found on line at www.aapidp.com.ar

Support IPOPI by visiting the IPOPI web site for plenty of information on PID. They are in a position to provide member organizations with empirical data. **A**



Young adult patients of the world

The Alliance

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.



B.C. Chapter CIPO 2007 by Mike Whelan



Change is in the wind

for the B.C. Chapter. After more than 2 years of monthly meetings we are considering

a change in format. Following the lead of Alberta we have started preliminary discussions to start a B.C. Chapter of Rare Blood and Bleeding Disorders.

Cindy Bell from AAMAC and myself have divided the list and are reaching out to the other groups to test their interest in participating in this new venture.

Nothing has been formalized at this point because we are still in preliminary stages.

I hope that we can agree to the national

objectives of the NRBDO, which are:

- Comprehensive care clinics
- A national registry
- Home care/self care programs
- Orphan drug policy

Doug Legasse is an accountant who specializes in Tax credits. He came to our May meeting and gave a presentation to the B.C. members on Disability Tax Credits, Canada Pension Disability and, Caregiver Tax Credits. The company is based in Vancouver and Toronto. Doug answered questions from the floor and gave out brochures and a client questionnaire. The questionnaire is a preliminary Q&A to see if there is a potential that you might qualify for the benefits.



Ontario Chapter Update

Tina Morgan, President of CIPO and also Chair of the Ontario Chapter, has been very busy getting provincial chapters set up across Canada, and now that she (along with a very dedicated group of volunteers) has accomplished this goal, she is free to concentrate on growing the Chapter in her home province of Ontario.

She is actively looking for volunteers to help organize regional patient support meetings over the course of 2008. An ambitious schedule is being put together, and Tina needs help to get notices out to area hospitals, doctors, nurses & patients. If you want a meeting in your community and would be willing to help Tina on site with organizing, getting word out, or any number of areas she would be grateful if you would either call her via CIPO at

1-877-262-2476 or email her at tina.morgan@cipo.ca.

Meetings are tentatively being planned in the following areas.

1. GTA East1, (Oshawa, Scarborough, Whitby, Don Mills, Downtown East)
2. GTA East2 (Peterborough, Port Hope, Cobourg, Belleville, Trenton),
3. GTA West (Toronto West, Etobicoke, Mississauga, Oakville, Brampton)
4. GTA North (Barrie, Alliston, North York, Richmond Hill, Orangeville, Caledon)
5. Ontario SW 1 (Hamilton, Niagara Falls, Burlington, Brantford, Stoney Creek, St. Catharines),
6. Ontario SW 2 (Cambridge, Kitchener-Waterloo, Guelph)
7. Kingston Area,
8. Ottawa Area,

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

9. Central Ontario (Sudbury, North Bay, Huntsville, Parry Sound)
10. Northern Ontario East, (to be held in Thunder Bay)
11. Northern Ontario West (to be held in Timmins)

