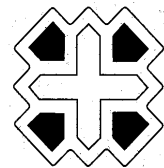


Canadian Porphyria Foundation

Increasing Knowledge Improving Health



Summer 2007

National Newsletter

Rare Disorder Forces a Life in Darkness

Once the sun goes down, a new world opens up for this spritely 4 ½ year-old. Once the sun goes down, Kasey and her family take walks outside, and do things other people do, during the day. Kasey suffers from an extremely rare genetic disorder called CEP-- congenital erythropoietic porphyria. Exposure to sunlight, fluorescent light, halogen light, any kind of ultraviolet light, can cause burns, blisters and scars.

When Kasey was born, problems developed. "She was swelling and a little red. They had her under lights to keep her warm," said her father, Kurt Kanuff. They sent her to a trauma center and put her head under the blue "bilirubin lamp," commonly used for jaundice. "She swelled three times her size. She turned red, blue, black and blue from head to toe. Nobody knew what was going on. They thought maybe she had a virus. It took about two-and-a-half-weeks before they came up with a diagnosis," Kurt Kanuff said. By that time, Kasey was burned all over her body. But the Kanuffs feel lucky she's alive, lucky that a local dermatologist happened to know about CEP, considering that there are fewer people than 100 people in the United States who have it.

Porphyria has eight different manifestations, all resulting from an enzyme deficiency in the production of heme, essential for metabolizing certain proteins. This deficiency causes toxic compounds, or "porphyrins," to build up in bone marrow, red blood cells, certain organs, and skin. And while symptoms vary, reddish-purple urine, purple teeth and abdominal pain are common to all porphyria. King George III of England suffered from an acute version of this disorder. Both parents need to carry the rare gene in order for a child to have it.

Kasey's house is protected by UV film on the windows and incandescent lights of no more than 50 watts. The same UV filters are in the van her parents use to take her to her myriad of doctors. Among other problems, her scars don't grow with her body. At one point, her thumb was growing inside her arm. "Mainly," says her mother Brenda Knauff, "we've tracked down doctors ourselves, found plastic surgeons...and they did the skin grafts and plastic surgery. Kasey has had seven surgeries so far. She doesn't like to talk about it, but her father is thrilled with the result of the surgeries. "Now she can touch her thumb and her pinky!" he said. The only known cure for CEP is a bone marrow transplant. A match for Kasey has not yet been found. And such transplants are risky. Recent publicity of Kasey's story helped put the Knauffs in touch with another CEP patient who suggested they look into blood transfusions. Her mother is hopeful this might make a difference. "If she does blood transfusions, she could relatively live a normal life," Brenda Knauff said. "She'd just have to go

to the hospital every couple of weeks, get blood work done and then live a normal life. We'd just have to monitor her hemoglobin level."

They have recently been talking to Dr. Robert Desnick, a leading CEP specialist at Mt. Sinai Hospital in New York. He hasn't seen Kasey yet, but thinks she may be a candidate for transfusion. The goal, he said, is to "Decrease the toxic compound that causes photosensitivity." Her parents are also speaking to the local school about making it safe for Kasey to attend, and they are slowly exposing their daughter to a little more light, one day at a time.

Reprinted with permission from CNN.com

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👉 **June 1st 2007**
👉 **National Porphyria Day**
👉 **Theme "What is Porphyria"**
👉 **The 3rd Celebration**

👉 Celebrate with us at:

👉 **National Office Open House**
👉 487 Walker Avenue
👉 Neepawa, Manitoba
👉 Friday, June 1, 10am - 4pm
👉 "Come and bring a friend"



👉 **National Porphyria Day Winnipeg**
👉 At Teddy Bear's Picnic
👉 Assiniboine Park, Winnipeg, Manitoba
👉 Sunday, May 27
👉 "Distribution of CPF pamphlets for children and their teddy bears"

👉 **National Porphyria Day Nova Scotia**
👉 Support Group Meeting
👉 Superstore in Bedford, Nova Scotia
👉 (next to the Bedford Place Mall)
👉 Saturday, June 2, from 2 - 4pm
👉 Theme: "Learn how to be sun safer"
👉 See you there!



Porphy Partners

By Bill Humphreys

Hello! I suffer from porphyria too. Not that I have the disorder myself, but my wife does, so that makes me a 'Porphy Partner'. It's a challenging role and I feel a word of encouragement is timely for you who also have relatives with this mysterious malady. You may be a husband, wife, brother, sister, son, daughter, father, mother, uncle or aunt. Or it may be you are just a good friend of someone with porphyria. Whatever the relationship, you find your life affected because you are so close to the sufferer. That makes you a P.P. (Porphy Partner), too. Welcome to a distinguished club.

Porphyrics can be very lonesome because of the nature of the disorder. They are often misunderstood and can be made to feel neurotic because there is no 'apparent' cause for the pains they experience. Our role as Porphy's Partner is one of encouragement and support. It's something that we have to work at and accept as a daily challenge if we are to be really helpful to the Porphy with whom we live. I am still learning in this area, but I would like to share with you four things that have helped me in my supportive role as a Porphy Pal to my Porphy Gal. I'll list them under four big 'P's. Pity, Patience, Persistence, and Prayer.

Pity. My poor Porphy needs pity. That is sympathy and understanding. Her pains and discomforts are very real and can sometimes be intense. We all know how ugly self pity is and my Porphy Gal seldom complains about her suffering. She has learned that self pity discourages pity from others. On the other hand her acceptance of her condition, and her quiet courage, is beautiful and generates greater compassion from her Porphy Pal. It really helps her, to know that I understand and care for her when the attacks come on. Let's call 'pity' LOVE IN ACTION, and by kind words and tender deeds demonstrate our concern.

Patience. Stress is a big factor in precipitating porphyric attacks. It can also prolong its duration and intensify its severity. Nothing creates more stress to a wife than an irritable, impatient husband, (or vice versa). So this P.P. has had to learn to be patient. It isn't easy! Remember the little poem: 'Patience is a virtue, possess it if you can; It's sometimes found in women, but never in a man.'

If I want my Porphy Gal to be patient in her suffering then I must be patient with her suffering. It seems the key to patience is acceptance. Life was never meant to be easy, and there are always folk far worse off than we are, so accept things the way they are and be thankful. Your patience will alleviate your Porphy's stressful fear that she/he is a nuisance.

Persistence. Porphyria is a very persistent complaint. It cannot be cured but it can be controlled. So hang in there! This Porphy Pal must persist in every way to see that both he and she abide by the rules; me doing my part and helping her avoid the onset of attacks. When she begins to develop one of those barnstorming headaches, when she is over-tired or run down, I must insist that she gets the rest that she needs. Some Porphys are well-meaning in wanting to keep going, but they need help and encouragement to keep within their limitations. Us P.P.'s do well to learn with them, what these limitations are,

e.g. What medications may be taken, and what should not? How much sun can be tolerated, if any? I am a 'slow learner', but it's coming! I can now sense when it's time to call the shots and lovingly, but firmly, entreat her to wisdom. I may say, "Sweetheart, it's time for you to get some rest.", but I have to persist and let her know that I really do want her to give in, to relax and to lie down when necessary. So, we need pity, patience, and persistence.

Prayer. Someone said, "More things are wrought by prayer than this world dreams of." I can only speak from personal experience here and do not wish to intrude on my reader's religious convictions, but my Porphy Gal, and I, her Porphy Pal, have found boundless strength and encouragement through reading the Bible and praying together. God is very real in our lives and we are comforted daily. We have found it wonderfully true that by praying together we stay together. Porphyria can be devastating to personal relationships. I have so often fallen short of being the Porphy Pal I ought to be. But we are learning together and I believe the good Lord is giving me pity, patience, and persistence towards my Porphy Gal, in the measure I need, in answer to prayer.



A Heart-Warming Thank You

The Canadian Porphyria Foundation extends a heart-warming thank you to those people who responded to our appeal for funding in the last newsletter. Thank you for your financial support that is helping porphyrics learn how to prevent acute life threatening attacks.

The CPF is once again holding its annual raffle. We have many wonderful prizes and would like to extend our thanks to all of our generous donors. Tickets are only \$1 each, and will be sold until August 23. If you are interested in selling tickets or purchasing them you can contact the CPF, to win:

1. Citizen 20" T.V. with Built-in DVD player - Neepawa Shop Easy, Neepawa, MB
2. Queen Size Down Duvet - Happy Jack's Restaurant, Fort Erie, ON
3. Papertole Picture - Heather Wilson, Fort Erie, ON
4. Ladies Watch - Buffalo by David Bittor - Gibson's Jewellers, Ridgeway, ON
5. Asian Table Runner/Placemats/Linen Napkins (8) - Happy Jack's Restaurant, Fort Erie, ON
6. Woodscape Picture - Larry Wilson, Fort Erie, ON
7. Quilt and Shams - Canadian Porphyria Foundation, Neepawa, MB
8. \$50 Petro Canada Gas Card - Bill's Toyota, Fort Erie, ON
9. \$50 Petro Canada Gas Card - Bill's Toyota, Fort Erie, ON
10. \$50 Walmart Gift Card - Niagara Automotive, Fort Erie, ON

President's Message



Lois J. Aitken
Neepawa, Manitoba

Each year as we approach the Annual General Meeting, I like to take time to reflect on the accomplishments we have made over the past year in fulfilling our mission to improve the quality of life for those affected by porphyria. In 2006 we had remarkable member growth. The ethnic diversity was amazing.

Last year, the Canadian Porphyria Foundation (CPF) provided valuable services that made an impact in many communities across Canada, as well as internationally. We undertook the development of a porphyria patient registry of diagnosed individuals and families that will become part of a database that advances our knowledge of numbers of people with porphyria in Canada and internationally. The registry data includes: types of porphyria, date of diagnosis, sex and age of the patient, and the diagnosing doctor. This information offers a unique perspective to the first porphyria patient registry in Canada.

In 2006, we worked for the needs of porphyria patients giving quality service. We offered hope. We made awareness presentations, developed bilingual educational information, increased our website's informational pages and expanded fundraising events.

For years we have dreamed that a porphyria medical center would be established in Canada to help educate doctors about the porphyrias and to secure a place where patients can be diagnosed and treated. This year we were invited to attend a meeting of the Network of Rare Blood Disorder Organizations (NRBDO). The NRBDO is a coalition of national patient groups representing seven rare blood disorders, including por-

phyria. Three issues facing the network are: (1) awareness and knowledge of rare blood disorders, (2) the importance of patient registries, and (3) the need for drug adverse reaction reporting. The Network is currently working to develop Comprehensive Care Clinics in numerous cities across the country. Currently people suffering from rare blood disorders, like porphyria, do not enjoy universal access to health professionals to treat their conditions. It is the hope of the Network that Comprehensive Care Clinics will soon be set up in Toronto, Ontario and in Calgary and Edmonton, Alberta. We are pleased to be a part of this Network.

In reflection, it was a great year for building team relationships. It was awe inspiring to be a part of the volunteers who worked hard at distributing awareness pamphlets and helping with fundraising events. We were always looking and planning into the future to see how we could become more financially sustainable.

I would like to warmly and sincerely thank everyone who supported the CPF in the past and in 2006. I want to thank all of our donors and supporters. It is your spirit of giving that makes our organization possible. Your donations help ensure that our education and prevention programs will continue.

I am truly grateful for our volunteers. Your dedication and hard work have helped move the CPF forward. Thank you for your help. And I want to give a special thank you to the people who responded with financial support after our annual appeal in our Winter 2006 newsletter. Your gifts transformed into the Foundation's continued programs for another year.

Sincere thanks is extended to our Medical Advisory Board Members and our Professional Associates, our accountant and lawyer. Thank you for your important role in helping the Canadian Porphyria Foundation help others.

In closing, to use the words of a registered nurse who had over 40 family members diagnosed in 1949, "It behooves each of us who know about porphyria to help do something about it."

We are pleased to welcome Arlene Bucksoviich of Neepawa, Manitoba as Secretary to the National Board of Directors.

Canadian Adverse Reaction Monitoring

Health Canada monitors health and safety risks related to the sale and use of chemicals, drugs and vaccines, food, pesticides, medical devices and certain consumer products. Health professionals and **consumers** can report adverse reactions to Health Canada.

To access further information about adverse reaction reporting, visit Health Canada's web site at http://hc-sc.gc.ca/ahc-asc/media/reaction/index_e.html. To report an adverse reaction to **pharmaceuticals, biologics** (including fractionated blood products as well as therapeutic and diagnostic vaccines), natural health products and radiopharmaceuticals, you can visit the MedEffect website at http://hc-sc.gc.ca/dhp-mps/pubs/medeff/index_e.html and follow the links to file an Adverse Reaction Report online. Or you can call 1-866-234-2345 and you will be automatically connected to your regional Canadian Adverse Reaction Monitoring office.

Extending a Hand



Joyce Hastings lives in Edmonton, Alberta and is sometimes invited by Rexall Pharmacies Southgate to give presentations about porphyria to their student interns. Joyce says, "the students are all very receptive and interested in the information that is provided by the Canadian Porphyria Foundation and they like receiving our newsletter." After their meeting, "The students go back to their university to talk and make presentations to their classmates."

The CPF and porphyria sufferers thank you Joyce.

We welcome professional associate and chartered accountant, Ian Thomson from Neepawa, Manitoba to the Canadian Porphyria Foundation Advisory Board. Ian reviewed the CPF's financial books for 2006, donated "the Notice to Reader" as a community service, and offered his professional advice. His outstanding giving significantly helps our organization.

Thank you Ian!

What Can I Do To Protect My Children/Myself?

By Mavis Lewis-Webber

For maximum protection, the summer outdoor schedule could be restructured so the children play outside in the early morning and late afternoon. Children should not play outside unprotected between 10 a.m. and 3 p.m., even on cloudy days. Up to 80% of the harmful radiation can penetrate haze, light clouds and fog.

Apply sunscreen 15-30 minutes prior to sun exposure. The active ingredients need time to work in order to offer maximum sun protection. Sunscreen with a sun protection factor (SPF) of at least 15, and endorsed by the Canadian Dermatology Association should be used.



Ensure exposed tops of ears, nose, tops of feet and backs of knees are adequately covered. Outdoor swimming or water play could be set up in a shady area, after 3 p.m. Cover the children with sunscreen from head to toe and a heavy weight cotton

t-shirt should be worn over their bathing suits. Reapply sunscreen every 2 hours during all types of outdoor play, even if it is water resistant. Children should wear wide brimmed hats to provide protection to their face, particularly their eyes and ears and the back of their neck.

Babies under one year old should be kept out of direct sunlight. Adults should wear sunglasses that screen out UVB radiation to prevent eye damage and reduce the risk of cataracts.

Thank You

The CPF would like to extend our thanks to the **F.K. Morrow Foundation** for its generous donation to help the CPF continue to provide its much needed educational information, as well as to further the CPF's mission.

Canadian Porphyria Foundation



Donate Online
www.cpf-inc.ca

You can make a donation to the CPF by giving electronically on our secured site with your Visa or MasterCard by calling toll free to the Canadian Porphyria Foundation at 1-866-476-2801. An official income tax receipt will be sent to you by post.

Two Types of Porphyria By the Late Dr. Barry Tobe

Porphyria Cutanea Tarda (PCT)

Porphyria cutanea tarda is the most common of all the porphyrias. It is a skin disease and is caused by decreased activity of the final enzyme step in the heme biosynthetic pathway, called uroporphyrinogen decarboxylase (URO. D). This enzyme is present primarily in the liver although it is also found in the red blood cells. When its concentration is decreased or its activity inhibited there is an over accumulation of uroporphyrin and other highly carboxylated porphyrins which are concentrated in the skin. Due to their propensity to accumulate radiant energy through a photodynamic process, they can inflame the tissues and cause cutaneous symptoms.

In about 20% of cases, the disease is inherited as an autosomal dominant trait and associated with deficient activity of URO. D in both the red cells and the liver. The onset of this inherited disease is usually delayed into adulthood although cases can occur in children. About 80% of cases of PCT do not have a familial history and are called sporadic, toxic or acquired. There may, however, be a demonstrable genetic defect in many of these cases. This type of PCT is associated with deficient enzyme activity only in the liver, which itself may be involved in a pathologic state. Excessive alcohol ingestion has long been recognized as an important cause, possibly related to the development of chronic liver disease. Estrogen therapy may also be a factor in this disease. Viral infections, particularly the HIV and hepatitis C viruses have been implicated. PCT can occur in patients receiving long term renal hemodialysis. Certain halogenated hydrocarbons have been associated with PCT. These compounds which have been contained in fungicides and herbicides were often inhaled or ingested by accident. Iron overload states may cause or magnify the disease. In addition, hematologic diseases associated with abnormal red cell and iron metabolism are also important causes.

The predominant symptom is that of photosensitivity, with abnormalities on the areas of the skin exposed to light such as the face, the arms and the backs of the hands and wrists. There is irritation and blistering followed by increased skin fragility, hair growth, scarring and pigment deposition. These findings are not specific for PCT and are seen in other types of porphyria such as congenital erythropoietic porphyria as well as other types of skin disorders including a condition called pseudoporphyria. There is an overproduction of water soluble porphyrins, particularly uroporphyrins, and they spill out into the urine and bile. As a result, the urinary and fecal concentrations of these compounds are elevated. Urinary PBG and ALA excretions are unaffected and are normal. Plasma porphyrin concentrations are increased, particularly the uroporphyrin levels. During clinical remissions, these abnormal levels fall to normal.

It is often difficult to differentiate PCT from VP or HCP, even in the laboratory, as some patients with VP will not have elevated urinary PBG levels and plasma and stool exami-

Continued on page 5...

Allergic to the Sun

Most Canadians anticipate the hot summer months with hopes of spending as much time as possible outside “soaking up rays”. But for some Canadians, the sun’s rays cause nightmarish effects.

Sunlight has been proven to precipitate the disease porphyria - a rare disorder to Canadians. Porphyria is an inherited disease that can cause at least eight different and complex disorders, four of which are related to sunlight. The degree of photosensitivity can become very serious. Some symptoms are skin rashes, blisters on the face and hands (as well as other sun-exposed areas), bulbous sores, and scarring. Unfortunately, the ultraviolet light which damages your skin in porphyria is different (a longer wavelength) from the ultraviolet light which causes sunburn in other people. This means that the usual sunscreens do not work. For this reason, many families must turn to alternative treatment and preventative measures. Treatment can be quite successful, but depends greatly on the type of porphyria.

Although the exact number of people who suffer from the disease is not known, the Canadian Porphyria Foundation adds approximately twenty new people who have been diagnosed to their patient registry each month. This number testifies that it may be only knowledge of the disease, and not so much porphyria itself, that is rare.

In the “sunlight porphyrias”, an excess of porphyrins (a chemical that everyone’s body has) builds up in the bone marrow due to a malfunctioning enzyme. This means that for someone with these types of porphyria, even small amounts of sunlight can cause symptoms such as bleeding, sores, and scarring. But a malfunctioning enzyme can also cause excessive amounts of porphyrins to produce what are called the “acute porphyrias”. These symptoms are endless. Contact with a porphyrin build-up “trigger” can lead to abdominal pain, nausea, vomiting and loss of appetite. Although most won’t experience anything more severe than minor symptoms, an acute attack can include changes in the level of consciousness and various abnormalities of mental function, and muscle weakness which can lead to respiratory paralysis and death. Fortunately, this outcome is rare.

Prevention and knowledge of the disease are the most important factors in achieving a healthy lifestyle when living with a rare disorder. Many people may believe that once some-

one is diagnosed with porphyria by the available testing methods, then that person can be cured. This is a myth. Porphyria does not yet have a cure. However, there are many ways for someone living with porphyria to avoid an acute attack. Prevention is the key to a comfortable and healthy lifestyle, although certain sacrifices must be made. It is best to avoid any triggers such as severe dieting, alcohol, certain medications and drugs, toxic chemicals, exhaustion, and sunlight. For example, surgery is not an advised means of solving a symptom such as abdominal pain because an unsafe anesthetic could initiate a porphyria attack.

Another battle that those living with porphyria must face is the unwillingness of others to accept the disease. Canadian physicians are only recently becoming more aware of the growing number of porphyria patients, and because porphyria symptoms mimic many other disorders, misdiagnosis is common. The mission of the Canadian Porphyria Foundation is to “improve the quality of life for those affected by porphyria”. But spreading awareness is easier said than done. Funding depicts the speed at which the national charity can grow. Formed in 1988, the CPF is an inspiring example of what a committed group of dedicated volunteers and part-time staff can accomplish. The CPF obtains its funds solely from fundraising, donations, and grants. Luckily, contributing factors such as technology and an influx of South African doctors to Canada (who are trained in the porphyrias), are helping the Canadian Porphyria Foundation achieve its goal.

There is much more work to do. With a patient registry that grows daily, the small office in Neepawa, Manitoba works hard to provide sufferers and family members with the educational material they need. The CPF networks with people from coast to coast as well as globally. In fact, the Canadian organization has in recent years helped other countries form their organizations. Some major goals of the Canadian Porphyria Foundation are to have support offices in all major cities, print all of the educational material bilingually, and compile a Canadian safe and unsafe drug guide to distribute to patients and medical professionals. From day to day, the prime focus is to fulfill its mission, promote awareness, and keep up the positive, sharing influence that it has created.

The Canadian Porphyria Foundation would like to welcome anyone willing to volunteer to distribute pamphlets or needing more information to call the office at its toll free number, 1-866-476-2801. Remember to visit the website at www.cpf-inc.ca.

Suggestions

Suggestions have come into our office from members that a good fundraiser would be to sell Christmas greeting cards.

Please contact us at 1-866-476-2801 or by email at: porphyria@cpf-inc.ca if you would like to buy or sell.

Your feedback will determine the success of this project.

A Special Thank You

Ovation Pharmaceuticals’ generous donation to help the CPF produce its next four newsletters is greatly appreciated.

The CPF would like to express its gratitude for your substantial financial support.

Help! Help! Help! Wanted

We recently visited our Member of Parliament, Inky Mark at Dauphin, Manitoba. Mr. Mark graciously suggested a number of things that would help the Canadian Porphyria Foundation advance in its mission in, "improving the quality of life for people with porphyria".

Mr. Mark told us that if our members were to write to their Member of Parliament and cc to three other ministers of Health both provincial and federal, (show in the letter that it is being sent to three other people), there is a better chance of our application for funding being taken seriously.

So **Please Help** by writing your member of parliament and telling them about the work of the Canadian Porphyria Foundation, that the disease porphyria can be life threatening and that there is a great need for patient services of support and education. Send them your story.

Donate Your Points

Through the "Shopper's Optimum Charity Program", at Shopper's Drug Mart, you can donate all or some of your points to the Canadian Porphyria Foundation by talking to a cashier. Your donated points will be used by the CPF to purchase necessary supplies. Thank you for donating your optimum points.

Yes! I want to help the CPF continue to improve the quality of life for people affected by Porphyria!

This newsletter receives many compliments from individuals and medical specialists about its valuable, understanding, and compassionate articles. It expresses our values, accomplishments, and hopes for the future. Your financial gift expressed in a donation, bequest, or planned giving will ensure our newsletter continues.

Gifts can be made using a credit card by:
Calling toll-free: **1-866-476-2801**
Emailing: **porphyria@cpf-inc.ca**
Faxing: **1-204-476-2800**
Or Mailing:

**Canadian Porphyria Foundation
P.O. Box 1206
Neepawa, MB, Canada
R0J 1H0**

Glossary

Hematin — a blue to blackish-brown component formed in the decomposition or breaking down of hemoglobin.

Carbohydrate — sugars and starches. Carbohydrates are made up of carbon, hydrogen, and oxygen and are a main component of many foods.

Glucose — a major source of energy present in body fluids. Glucose is often used as a treatment for acute porphyria attacks.

Photosensitivity — increased reactivity of skin to sunlight caused by a disorder such as porphyria.

Dual Porphyrias — the condition of having more than one type of porphyria. This is rare, but possible.

Thank you Astellas Pharma Inc. for your donation to the CPF!

Family members donate funds to our organization in memory of their loved one. The CPF says "thank you" for your outstanding giving.

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Gifts made by cheque (made payable to the Canadian Porphyria Foundation) should be mailed directly to the Canadian Porphyria Foundation's national head office. Registered Charity # 11883 5305 RR0001

Coping Tips From An EPP Dad

My name is Kevin Gore, and my wife Cindy and I have a 3-year old son with EPP. He was diagnosed last year, so we are still learning about the disease and how to deal with it

We have spoken to other EPP families, and the consensus is that it is virtually impossible to get younger children to take Lumitene. We have found that, for our 3-year old son, mixing Lumitene in with Spaghetti-Os has proven very effective. The color hides the fact that the Lumitene is in there, and he doesn't mind the taste when mixed in.

Also, we have found a Compounding Pharmacy that was able to come up with a way of mixing beta-carotene with flavored syrup to make it easier for younger children to take. Our son Grayson is now taking the recommended 2 capsules a day, whereas before, he could not or would not take the Lumitene capsules. He is unable to swallow them at his age, and the flavor of the beta-carotene mixed with most foods is not very palatable with few exceptions (i.e. Spaghetti-Os, above).

The pharmacist looked up the manufacturer of beta-carotene used in Lumitene, and confirmed that the manufacturer he is using is Hoffmann-LaRoche (Roche), and it is the same 10% beta-carotene beadlets used in Lumitene. This is the manufacturer that supplies it for Lumitene. He then mixes it into capsules with sugar, and as you take each dose, it is mixed into a flavored syrup type mixture, which dissolves the beadlets. Our son prefers a Tutti-Frutti flavor, but the pharmacist can also use other flavors such as bubblegum. Even better, since he makes the capsules at the pharmacy, and uses prescription-grade beta-carotene, he was able to submit it to my insurance company and get it approved, whereas Lumitene could not be approved. I talked to the pharmacist and told him he may get requests for mail-order as people find out about this. He said that would be fine. If you are interested in looking into this, here is the information:

Matthew Buderer, R.Ph., FIACP
Buderer Drug CO.
26611 N. Dixie Highway, Suite 119
Perrysburg, OH 43551
Phone: (415) 873-2800 or (800) 259-6662; Fax (419) 873-0494
Printed with approval from the EPPREF NEWS

Often a gift of money is favoured because the charitable receipt can be used at income tax time.

Thank you volunteers for participating in fund-raising events and volunteering to distribute porphyria awareness pamphlets. Your assistance is helping give hope to porphyria sufferers.

Donation Thank You

Each small gift or large contribution to the mission of the CPF helps improve the quality of life for babies, children, youth and adults diagnosed with porphyria. Your special financial gifts have made a difference and we thank you.

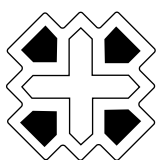


Neepawa United Way



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