
The Duct

Bringing you news on PSC

research, education, and support



PSC Partners Seeking a Cure Foundation

Fall 2008

A Foundation Milestone: Launch of First Competitive Research Grant Program Cycle

by David Rhodes, Board Member and Chair of the Scientific/Medical Advisory Committee

The PSC Partners Seeking a Cure Foundation is pleased to announce that it has reached an important milestone: release of a "Request for Proposals" at our website: <http://www.pscpartners.org/RFP.htm>.

This means that we are now formally seeking research proposals from PSC researchers to fund novel, significant research projects that promise to discover improvements in therapy for PSC patients and/or make progress towards finding the cause(s) and cure(s) for this liver disease. This milestone has been achieved about 3.5 years after the foundation was established (January, 2005). It means that we can

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Q and A with David Rhodes: Details of the Grant Process

Q. How much will the grants be for, and for how long?

A. We hope to fund research projects at a level of up to \$20,000 per year for a two year period. This means that the awards will be capped at \$40,000 each.

Q. How many proposals will be funded each year?

A. At present we anticipate that we would be able to sustain funding of about 2 or 3 proposals per year.

Q. How will the proposals be evaluated?

A. The members of the Scientific/Medical Advisory Committee will independently review each proposal according to how well each proposal meets the guidelines (described at <http://www.pscpartners.org/RFP.htm>) and holds promise for making significant advances in PSC research. The decision about which proposals to fund/not fund will be made by the committee, based on input from all members.

hope to have one or two projects funded soon after our 4th birthday (the first deadline for proposals is January 1, 2009).

Over the next month I will start to write to PSC researchers world-wide to inform them of the competitive grants program, guidelines and deadlines.

This has been made possible as a result of about two years of careful deliberation by the Scientific/Medical Advisory Committee (Drs. Greg Everson, Don Safer, Aubrey Goldstein, Steven Deitch and Dennis Black), and all of YOUR generous donations!

Research into the causes and cures for PSC will be costly and we can move forward with funding research only through your continued financial support. Many thanks for making this possible!

FROM RICKY SAFER, PRESIDENT OF PSC PARTNERS: A NEW SEASON

Autumn has arrived in all its splendor in the high country of Colorado. Right now, I'm enjoying a wonderful fall weekend in the mountains, hiking and biking under sunny blue skies filled with crisp fall air.

Viewing the changing of the leaves sparks my anticipation of another new season with all its promises. PSC Partners Seeking a Cure is also entering a new season with the excitement of numerous promising opportunities that have arisen recently.

✓ **Research Grant Program Launched:** During our foundation's first three and a half years of existence, we have been able to establish many successful educational and support

programs while continuing to work on our fundraising projects.

Thanks to all our PSCers and caregivers and their family, friends and colleagues who have donated to our cause, we are now launching our own research grant program to support researchers worldwide who will bring us closer to finding the cure for PSC. Please read David Rhodes' article on page one to learn about this exciting milestone!

Thank you to our Scientific/Medical Advisory Committee who created this important ongoing program and also to everyone who continues to donate to our cause .

✓ **PSC Research Prize:** This is the second year that PSC Partners Seeking a Cure is

awarding a prize to the investigator presenting the most promising PSC research at the annual meeting of the American Association for the Study of Liver Diseases (AASLD).

This year, AASLD has chosen two separate research projects to receive our prize at their October 31 meeting. The awards will be written up in the AASLD 2008 Annual Report. See page 14 for more details. Dr. Thomas H. Karlsen of Oslo, Norway, the recipient of our 2007 AASLD award and a speaker at our 2008 conference, continues to do outstanding research on the genetic basis of PSC.

✓ **Itching for a Cure Fundraising Challenge:** We are proud to be supporting novel research projects and playing an

integral role in eventually finding a cure for PSC. To bring us a step closer to our goal, I am thrilled to announce that we have an angel in our midst!!!

I have just been contacted by an anonymous donor who is offering us a phenomenal fundraising challenge.

This donor has offered to match every donation we receive to The Road to Chicago fundraiser starting now until our conference (May 1-3, 2009). This is a dollar for dollar match, up to the amount of \$45,000!!!!

The donor and donor's family decided that this was how they wanted to use the gift left to them by their parents/grandparents.

This is an incredible opportunity for all of us as a group to pitch in and donate whatever we can, to contact family and friends, or to hold local fundraisers. All donations, no matter the amount, are welcome.

To help us reach this \$45,000 fundraising challenge, join us in the Itching for a Cure Fundraising Challenge (a part of The Road to Chicago fundraiser). To donate, just earmark your donation for the Itching for a Cure Fundraising Challenge. See page 28 and the website for more details.

Let's join our anonymous donor by completing this challenge. We can continue to increase the scope of our grants program and eventually find that elusive cure!!! Together, we can do it!

✓ **Local Fundraising Efforts:**

I'm overwhelmed with the personal fundraising projects that some of our members have organized. In the past six months, these four projects have been a huge success:

- The Rummel Family of Sherborn, MA, organized a bike ride in June which raised \$12,611! Read more on page 34.
- The Katy Miller family of Creekside, PA, held a walk in April, which raised \$8,032 and a golf outing this summer which raised \$3,220! Both events were held in memory of Katy Miller.
- Friends of Mike Zaloudek of Severna Park, MD, participated in a bicycle race, The Race Across America, which raised \$8,800!

In addition, here are some other creative fundraising projects:

- Reggie and Jeff Belmont of Cheshire, CT, continue holding monthly Film Fests at their home. They rent a film, provide snacks and invite friends to join them and bring a donation.
- Shelley Hussey of Acworth, GA just had her entertaining and insightful book published, and she is sharing a portion of her book sales profits with us.
- Nichole Rowland of Mt. Holly, NC, sold roses at her

daughter's spring dance recital. For the Christmas holiday, she is selling Webkinz and sending all profits to PSC Partners.

- Heather and Susan Lenihan of Plano, TX, are holding a Pampered Chef cooking show and donating the profits to the foundation.

- Quickstar Productions of Baltimore, MD, created a CD from a variety of bands, and they continue to send us a portion of the proceeds from sales of the CD.

I'd like to send a heartfelt thank you to all these PSCers and caregivers who are supporting our cause!!! If you would like to think about doing a local fundraiser, please contact Lee Bria at leedeubert@gmail.com or Ricky Safer at contactus@pscpartners.org to discuss your idea. We'll then ask you to fill out our short Project Proposal form.

✓ **Web Redesign:** The Cordis Corporation, a subsidiary of Johnson and Johnson, continues to support our programs. They have just awarded us a \$9,000 grant to hire a web designer to redesign our website.

For the past three and a half years, David Rhodes has worked tirelessly to create and maintain both our excellent websites: www.pscpartners.org and the PSC Literature site. The new design and organization of our

main website will give us an even more professional look, an ease of navigation and greater access to PSCers, caregivers, physicians and researchers.

✓ **New Diagnosis Brochure:** As continuing progress from last year's grant from Cordis Corporation, we are about to publish our second brochure in a series of four.

David Rhodes has written the text for our brochure on PSC Diagnosis. Pat Bandy and Shelley Hussey are currently working on the final draft and George Schill has created our cover illustration. This brochure will be a great help to anyone in the midst of the often tedious and anxiety-filled process leading up to a PSC diagnosis.

I'd like to personally thank Cordis Corporation for their support of our educational programs!

✓ **Original Holiday Cards Offered:** Another stroke of good luck for PSC Partners is the arrival of American Greetings artist and writer George Schill, of Monroeville, PA, a new volunteer who has already added a new dimension to our foundation.

George is an extremely talented professional illustrator who has created our two whimsical holiday card designs, the cover illustration for our newest brochure and the title and logo for our Itching for the Cure Fundraising Challenge.

Please think about ordering your holiday cards from us while helping us in this easy fundraising effort. Proceeds from the sale of the cards benefit the research, educational and support programs of PSC Partners Seeking a Cure. (See page 6 to view and order the holiday cards.) Thank you George for sharing your talents with all of us!

✓ **2009 Conference:** Becky Long and I are continuing to work on the final details for our annual conference to be held May 1-3, 2009 in Chicago. We have a terrific conference weekend planned, so please mark these dates in your calendar and try to join us. I'll keep you updated as soon as our plans are finalized.

✓ **2010 Conference:** We are already looking ahead to our 2010 conference. If you might be interested in hosting that conference, please take a look at the Guidelines for Hosting the 2010 Conference that are posted at: <http://www.pscpartners.org/Conf2010Guide.htm> If you have any questions, feel free to write to me at contactus@pscpartners.org.

✓ **Cholangiocarcinoma Foundation Link:** Recently, I was contacted by Stacie Lindsey and Sara Hinkley of The Cholangiocarcinoma Foundation. They are a young foundation (two years old) with the goals of advocacy, education and support for people dealing with cholangiocarcinoma. We are hoping to cooperate on some programs in the future. Please take a look at their very helpful website at www.cholangiocarcinoma.org.

✓ **Organ Donation Awareness:** I've also been working with Morgan Ilika at the Chris Klug Foundation. We're working on ways in which PSC Partners' members can help with or participate in some of their local organ donation awareness projects.

I have posted an announcement for their Summit for Life event to be held in December, which Don and I hope to attend. If you live in Colorado, perhaps you can join in this fun event to encourage organ donation.

✓ **International Symposium:** Dr. Karlsen of Norway is keeping us updated on plans for an international symposium on PSC to be held in Oslo June 21-23, 2009. The slate of speakers is superb, and the talks will be held in English. A few of us are hoping to attend the meeting. Dr. Karlsen said that we are welcome to join them, but that we need to be aware that the presentations are of course aimed at hepatologists.

We feel so fortunate to have the support of all of you! If you are looking for a way to continue your support, please help us in any way that

works for you: by purchasing holiday cards, helping us fundraise for the Itching for a Cure Fundraising Challenge, offering your special skills, planning to join us at our May 2009 conference, or by sharing any ideas you have for future directions for PSC Partners Seeking a Cure.

Remember our motto . . . Together in the fight, whatever it takes! Wishing good health to everyone.

Ricky Safer
President, PSC Partners Seeking A Cure

OLYMPIAN CRIS KLUG'S SUMMIT FOR LIFE SNOWSHOE RACE AIMS TO INCREASE ORGAN DONATION AWARENESS

Mark your calendars now and start hiking: get ready for the 3rd Annual Aspen Summit for Life Saturday, Dec. 6, 2008. The Summit for Life is an uphill snowshoe race and celebration of life to promote organ and tissue donation, benefiting the Chris Klug Foundation. "It's a fun way to help raise awareness for organ and tissue donation and help support CKF's educational outreach," says liver transplant recipient Chris Klug, a PSC-er, and liver transplant recipient.

Summit for Life will be a weekend of activities promoting awareness and education of organ and tissue donation. The weekend will be centered around the uphill race, which starts at the base of Colorado's Aspen Mountain on December 6, 2008. Racers will climb 3,267 vertical feet over 2.5 miles from the base of Aspen Mountain to the Sundeck on top. Racers of all ages and ability levels are encouraged to participate. Prizes will be given to the top three men and women finishers and the top team. Awards will also be issued to the top three fundraisers.

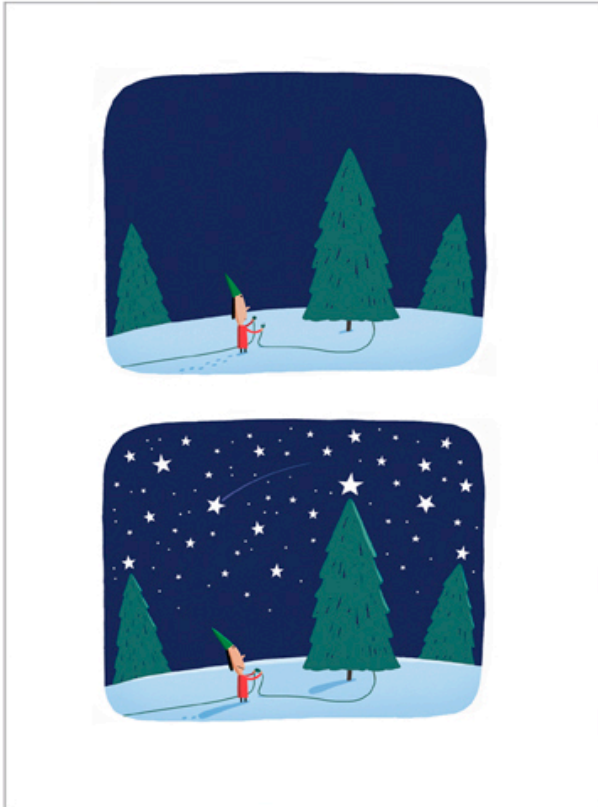
The cost to register for the race is a \$40 required registration fee on or before Friday, December 5th and \$50 the day of the race. By registering you are also committing to raise \$160 in requested pledges, however, there is a minimum of \$60 in pledges required. People who want to skip the hike but still want to be a part of Summit for Life have two options. "Ride for Life," \$60 buys you a ride on the Silver Queen Gondola to the summit to enjoy dinner, drinks and dancing at the Sundeck, or "Snowed In," is a way to support Summit for Life from the comfort of your home.

To register for the uphill race, donate to the cause or to learn more about Aspen Summit for Life 2008 visit: www.summitforlife.org.

For more information about The Chris Klug Foundation check out: www.chrisklugfoundation.org

ORIGINAL 2008 HOLIDAY CARDS NOW AVAILABLE

We are delighted to offer two unique holiday cards for sale. They were designed by American Greetings artist and writer George Schill especially for PSC Partners Seeking a Cure. All proceeds from the sale of these cards will benefit our research, educational, and support programs. Please send in your order now!



Starry Night card

Design copyrighted by George Schill

ALL ORDERS MUST BE RECEIVED BY NOVEMBER 7 AT THE LATEST!!

At this time, the cards will go to print, and will be shipped to you right before Thanksgiving (November 27).

Inside:

May Your Holidays Sparkle with the Magic of the Season

The holiday cards are available in packs of 25 at a cost of \$35 per pack plus shipping and handling. For domestic orders, shipping and handling is \$5 for an order of 1-2 packs and \$10 for 3 packs or more.

For international orders, please email contactus@pscpartners.org and a shipping quote will be provided.

Snowman card

Design copyrighted by George Schill

The cards are 5"x7" in size and they include white envelopes. The packages will be shrink wrapped.

To order the cards, please go to our website:

<http://www.pscpartners.org/Holidaycards.htm>

and fill out the order form. You may send your order and check to:

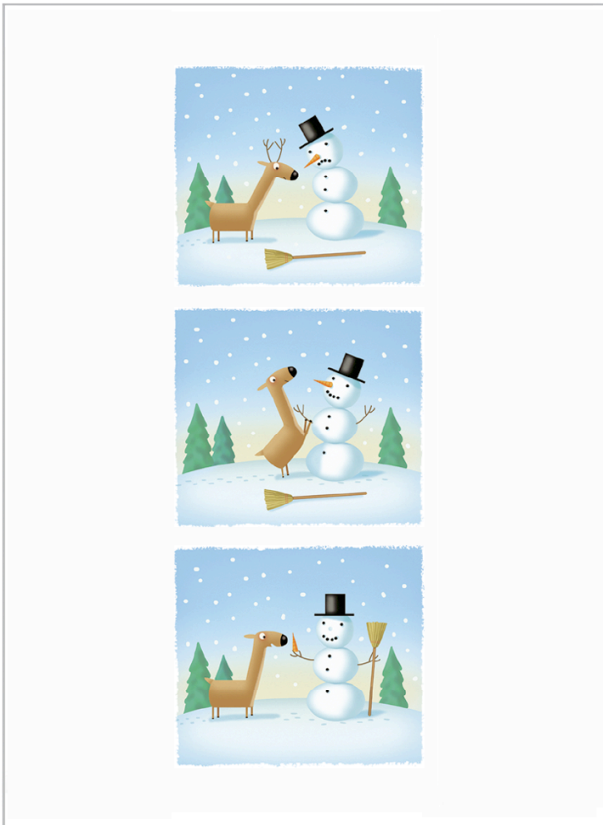
PSC Partners Seeking a Cure
5237 So. Kenton Way
Englewood CO 80111

OR you may order online directly via Paypal email:

http://www.pscpartners.org/Holiday_card_order_form.pdf

If you have any questions about your order, please write to us at contactus@pscpartners.org

Remember the November 7 deadline!



Inside:

Share the Spirit of the Season

Back of both cards:

Proceeds from the sale of these cards benefit the research, education, and support programs of PSC Partners Seeking a Cure. To learn more about Primary Sclerosing Cholangitis go to www.pscpartners.org.

Speaking of Holidays, Here's a Gift Idea from PSC Partners . . .

The Foundation offers notecards on the website at <http://www.pscpartners.org/Notecards.htm>. These are perfect stocking stuffers, or gifts for office mates, a teacher, a neighbor.

A package of six note cards for \$10! What a deal!

Caregiver Corner

The Caregiver's Bill of Rights

The origins of the "Caregivers Bill of Rights" are a bit murky, but the statement recognizes the important job caregivers perform. Caregivers are very special people who give us a reason to live and are the people we live for. They are unsung heroes who don't think of themselves as doing anything special, they're just taking care of a loved one.

It's a tough job, often accomplished in difficult circumstances. When a caregiver's needs are met, the person he or she is taking care of benefits, too. PSC Partners Seeking a Cure salutes all caregivers of PSC-ers and recognizes their quiet dignity.

A Caregiver's Bill of Rights

I have the right . . .

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.*
- To seek help from others even though my loved one may object. I recognize the limits of my own endurance and strength.*
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.*
- To get angry, be depressed, and express other difficult feelings occasionally.*
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt and/or depression.*
- To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.*
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.*
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my love one no longer needs my full-time help.*
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.*

Respond to: newsletter@pscpartners.org. Tell us what you'd like to read about regarding caregivers in future newsletters. If you have particular tips or a special point of view, why not share with others?

MY WORDS, MY STORY

Short but Wide

*by Melvyn, 20 years old, PSC
diagnosed in 2005, Tehran, Iran*

Many eyes cry for my destiny
Many ears listen to my words
Many mouths talk to bring me
hopes
Many hearts ache for the oceans
of my sorrow
Many dears pray for my lost
health.

Long time ago
I'd been looking for people
To cry
To listen
To talk
To pray
To do anything for me
To tell me I'm not failed
To tell me I won't die

It was my wish to make the
BESTs
But now it's just a chance to
breathe no matter how.

I've forgotten how to smile since
then
Maybe it's the answer to a friend
asking me to smile.

Someday I found there's no more
need
To have listening ears
To have crying eyes
To have talking mouths
But I saw it's just PSC who
should listen who should cry and
talk

Another wish
I don't want anyone
understanding
I want my PSC to understand my

tears

I want my PSC to remember my
forsaken love
I want my PSC to go before I do

Will someone come tonight from
the sky to answer?
That: Why me?

I found a reason to smile
That it's me

It's me who's suffering
Not my dears
So I smile to their tears
That it's me who's the reason for
tears not them
And I'm happy with their health

No matter how short my life will
be
But it matters that how wide it
was.

Attention all 20 and 30-Something PSCers (or those nearly in that range!) and Facebook Fans:

If you haven't already, now is a great time to join the PSC Partners Facebook page! Get in touch with other PSC-ers your age to share concerns, ask questions and discuss what life is like when you're young and diagnosed with PSC. If you've ever needed a place to complain about the fact that you need to nap when all your friends want to do is go out and party, share how you deal with drinking, ask others about issues dealing with starting a family, etc., here's the place for you! To join, simply log onto www.Facebook.com and follow the prompts to set up a free account. It's simple to do and just takes minutes. Once you have your account, just type in PSC Partners in the search box under Groups and you'll be taken to the page. It's just that easy! Hope to see and hear from you soon!

A Gold Medal Achievement at the Canadian Transplant Games

Caroline Vanneste, wife of Scientific/Medical Advisory Committee member Aubrey Goldstein, writes about the inspirational experience of attending the Canadian Transplant Games in 2006 and Aubrey's recent athletic achievements at the 2008 Games.

Aubrey Goldstein of Ottawa, Ontario has a lot to celebrate. After suffering from PSC for eighteen years, he received a liver transplant on May 10th, 1998. Marking ten years of good health with family and friends this past spring, Aubrey remarked that his donor didn't just save his life, she gave him a new one. Years of PSC-induced fatigue caused him to cut back on, and eventually cut out, the sports and active lifestyle he loves. But after his transplant, it was back to tennis, skiing, cycling, hiking, canoeing, skating...the list is endless!

Helping transplant recipients to maintain a healthy lifestyle is what the The Canadian Transplant Association is all about. The registered charitable organization supports a variety of athletic events for transplant recipients, but its most prominent is the Canadian Transplant Games.

These games were first held in 2000 in Sherbrooke, Quebec, and are held every second year, in alternate years from the World

Transplant Games. Transplant Games are Olympic-style sporting events in which organ transplant recipients compete against each other. It gives recipients incentive to stay fit, a chance to meet other recipients, and the opportunity to show the world that organ donation really works!

Aubrey will never forget his experience at the first Canadian Games. Meeting so many other transplant recipients, who had similar health issues to laugh and cry over, led to wonderful memories and lasting friendships. (In that way, it is much like the PSC Partners Annual Conference!) And for an avid athlete, it was also great to win a few medals. He repeated that feat at the Games in Edmonton, Alberta in 2006, and had his best ever Games in 2008.

This year's Games were held from August 4th to 9th in Aubrey's home town of Windsor, Ontario. He was thrilled to have the opportunity to show his "transplant friends" where he grew up, and to show his "other

friends" how fit and active transplant recipients can be. He competed in tennis (singles and mixed doubles) and golf, two long-time passions, and his new addiction of cycling. He amazed and impressed everyone - including himself - by winning gold medals in all four events! It was definitely a week to remember, with all that hardware and the chance to catch up with Canadian and American transplant friends.

The U.S. also holds national Games in alternate years from the world Games, and the two countries allow athletes from both countries to compete. In addition to reconnecting with athletes from Ohio, Virginia, and Louisiana, Aubrey was thrilled that PSC Partners' board member Dike Ajiri popped by for the opening ceremonies. Despite urging from his American friends, Aubrey has yet to make it to the U.S. Games, but it's on the list! So many Games, so little time...

Time will definitely be needed to compete in the world Games

next year, as they are being held in far-away Australia. Aubrey and his wife had planned to travel through Australia and New Zealand for three months in the year before his transplant, but had to cancel the trip because he was too ill. It seems fitting that the long-postponed trip will be rescheduled in order to attend transplant Games.

Aubrey encourages all transplant recipients to participate in transplant Games. There are athletes of all sizes, ages, and ability. There is something for everyone. And for those of you who are currently waiting for a transplant or may some day face a transplant, try to attend a transplant Games. You will be inspired by how good your life can be after transplant. Organ donation works!

For more information on the Canadian Transplant Association and various transplant games, see the following websites:

<http://www.organ-donation-works.org/>

<http://ctawindsor.org/>

<http://www.kidney.org/news/tgames/index.cfm>

<http://www.worldtransplantgames09.com/>

Aubrey is awarded his gold medal alongside his fellow American gold medalist.



The Duct's Poll

Gastroenterologist or Hepatologist: Which do you prefer to treat your disease and why?

We wondered which specialty you have looking after you. Gastroenterologists treat the entire digestive system and hepatologists treat only the liver.

Respond below and we'll compile the results and report back in the next issue.

Send your thoughts to: newsletter@pscpartners.org

Resources

Two of the Best Medical Terminology Web Sites (plus 1 more)

Any medical condition, from managing a cold to dealing with PSC, has terms we don't use in everyday conversation. In order to read your reports or keep up with the medical team taking care of you, you need to understand a new language: *Medicalese*.

That's when a handy, easy to use on-line dictionary or encyclopedia can be of a real assistance.

There are hundreds of medical dictionary sites on the web to check out, but two of the simplest, most elegant sites—and the most reliable—are from the US government's National Institutes of Health: the MedlinePlus websites.

There are no advertisements to jeopardize the site's integrity, the sites are kept updated, and illustrations and diagrams are easy to comprehend.

The MedlinePlus Medical Dictionary

A clean, neat page loads; after typing in the medical term you

instantly receive a list of variations of that term. The entry offers a history of the word in medicine.

We chose a word familiar to PSCers, "stent" to compare across several sites. The entry in MedlinePlus tells us that the word "stent" originally referred to a dental impression compound developed by British dentist Charles Thomas Stent.

The site offers pronunciation help and variations you might hear, such as "stint." The definitions are in plain English and easy to understand.

<http://www.nlm.nih.gov/medlineplus/mplusdictionary.html>

The MedlinePlus Medical Encyclopedia

The encyclopedia site is similarly brilliantly helpful and user-friendly. On the first page you click the alphabet letter for the word you are researching.

The encyclopedia entry for the word "stent," in contrast to the dictionary site, offers more information: alternative names, a definition, a description of the procedure, illustrations of stents, risks, and additional citations for further research.

<http://www.nlm.nih.gov/medlineplus/encyclopedia.html>

The Medicalese Dictionary

And finally because laughter is the best medicine, just for fun, check out this site: a humorous medical dictionary put out by Medi-Smart a nursing education resource. The site defines such terms as "wallet biopsy" and "G.O.K." (God Only Knows). Enjoy!

<http://medi-smart.com/medicalese.htm>

We Support Organ Donation

One of our foundation goals is to increase organ donor awareness. We encourage U.S. readers to visit www.donatelife.net and click on their state.

This site gives a state-by-state guide to the organ donation process.

This would be a good place for our members to start thinking about how to help locally, if they are interested.

Donated organs and tissue are shared at the national level; the laws that govern donation vary from state to state.

Therefore, it is important for you to know what you can do to ensure your decision to be a donor is carried out.

WHAT ISTHAT LAB TEST TELLING ME?

For this article we thank our great friend Ivor Sweigler, Ph.D., of London, who is Chair of PSC Support. PSC Support is similar to PSC Partners Seeking a Cure in the UK. It is a group of patients and medical professionals who seek a better understanding of the disease and additional research.

Ivor is editor of the voluminous newsletter, PSC News (Available online by subscription at \$40 per year. It contains medical and support information). The group's website is www.psc-support.co.uk

Our friends across the pond face the same PSC issues and we are "Together in the fight, whatever it takes."

Liver Function Tests

If a liver problem is suspected, one of the first things your doctors will do is test your blood and examine the results of your liver function tests, or LFTs. If the readings are above the normal ranges you may have a liver problem, although several of the results may also be elevated if you have bone or cardiac problems. The tests don't indicate what type of liver problem you may have and further tests must be done.

The LFTs will include:

GGT

Gamma-glutamyl transferase (but you don't have to bother with the

big names; everyone uses the initials GGT). This is an enzyme found mainly in the liver and is very sensitive to changes in liver function. If the liver is injured (as a consequence of liver disease), or there is an obstruction, GGT levels rise. It is the most sensitive liver enzyme for detecting bile duct problems. For most of us this will be elevated above the normal range because PSC involves inflammation and damage to the bile ducts.

ALT

Alanine aminotransferase An enzyme mainly found in the liver. Elevations usually indicate bile duct problems.

ALP

Alkaline Phosphatase An enzyme related to the bile ducts. It is typically elevated when there are bile duct problems, blockages, dominant strictures etc

None of these tests tell us about how the liver is **functioning**. But the tests that do tell us are:

Bilirubin

This is the yellow breakdown product of red blood cells. They last for about four months after which the red haemoglobin breaks down into bilirubin. This is a function of the liver. The **unconjugated bilirubin** is carried to the liver. Sugars are attached and **conjugated bilirubin** is then passed into bile by the liver.

Elevated levels of bilirubin indicate that the liver is not performing this function well. Jaundice begins to appear when these levels increase in the blood. Normally the bilirubin is further broken down and excreted in the stools which give them their characteristic color. But if you become jaundiced the stools become grey (and the urine dark-red wine colored).

Albumin

This measures the main protein made by the liver. If the liver is not making adequate amounts the test result will be below the normal range. Albumin is particularly important in regulating blood volume, carrying hormones, bile salts, iron, fatty free acids, etc

PT and INR

(prothrombin time and international normalized ratio)

This measures how long it takes plasma to clot with a usual reference range of 12-15 seconds. The clotting process is also a function of the liver.

Total Protein

This measures albumin and all other proteins in the blood including antibodies which help to protect against infection.

In a similar way to blood pressure, these test results will vary over time and they can be affected by such things as vigorous exercise or high levels of tea consumption. If you keep a record you need to look at the trend over some months. The test result forms are easy to read because they include the normal ranges. Most of us notice that with high-dose Urso the elevations are reduced – and the results can go back to the normal range.

There are a number of useful websites. See for example, Lab Tests Online (www.labtestsonline.org) There are many other blood tests that your doctors may order but these are the main ones. We should all be monitored on a regular basis.



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