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Bringing you news on PSC



PSC PARTNERS
SEEKING A CURE

research, education, and Support

PSC Partners Seeking a Cure Foundation, Spring 2010

Google Funding \$50,000: Will Help Accelerate PSC Research, Provide Therapies to Patients

By Tom Hill, PSC Partners Project Coordinator for the Google Project

Editor's Note: See related story on the NIH patient registry workshop on page 6.

In the summer of 2009, I was talking with a friend in the Google Health group about the problems that PSC researchers and patients face in accelerating the research and therapy development process.

There was a long time gap between when researchers are able to recruit enough patients (with PSC patients spread throughout the country in small numbers) to make the study statistically significant, run the study, get the results, determine findings and communicate those findings to patients.

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Reminder: Important Conference Hotel and Registration Dates

Conference discount rate: On or before April 12 the rate is \$150 per person, \$280 per couple, \$140 for each additional family member or caregiver **Late:** After April 12, \$170 per person, \$320 per couple, \$160 for each additional family member or caregiver. All conference fees must be received by May 1.

Hotel discount room rate: The reserved room block will be allocated on a first-come, first-served basis. **The cutoff date for the discounted group rate is April 23.** The special group rate will expire when all allotted rooms have been reserved or on April 23, whichever comes first.

You can still register after these dates, but not at the lower rate.

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Then, we thought, why not use Google Health and a companion program to facilitate communication between researchers and patients, and to even help in the recruitment and identification process. Plus, the Google Foundation might even fund the development of the software application.

I discussed this idea with Dr. Chris Bowlus, PSC researcher at UC Davis, and invited him to be the Principal Investigator on the project. Chris quickly agreed and work began during the summer to meet the grant proposal August 15th deadline.

We appreciate Dr. Bowlus's work on the project and sponsorship of the UC Davis medical school, which has proven to be crucial to our success in obtaining the grant.

After submission, the proposal team was told that the proposal was not typical of other research awards, so we figured it was a long shot.

After a few months, the Google Health Product Manager sent a message asking if PSC Partners could secure support funding, if Google provided the software development funding.

I called Dr. Bowlus, and he was successful in obtaining support from the Informatics department at UC Davis with the help of Prof. Mike Hogarth.

In the third week of January we received a letter from the Tides Foundation, which was administering the grant for Google, telling us that we had received the funding.

In February, we held our first project kickoff meeting that included the Google Health Product Manager, Roni Zeiger, Google Health Development Manager, Marc Donner, Google VP of Research – Special Projects, Alfred Spector, Dr. Chris Bowlus, and me. The team has completed the assessment of researcher and patient needs, and now a

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The \$50,000 Grant from Google

PSC Partners Seeking a Cure recently announced a grant award from the Google Foundation to build a PSC Researcher-Patient Network (RN) to accelerate the development of PSC therapies, treatments, and standards of care.

The RN software will be designed to assist researchers in identifying new PSC patients, registering them, and recruiting them for studies. In addition, patients will be able to receive the latest information on research, and participate in educational virtual seminars led by recognized PSC researchers.

Project leaders expect the RN software to be foundation technology in accelerating the emergence of a robust researcher- patient community working together to discover cures for PSC. PSC Partners President, Ricky Safer noted, "We are grateful to Google for making this funding available to us to build the Researcher Network, that will leverage the partnership between patients and researchers in the search for new drugs, therapies and standards of care for this life threatening illness that affects men and women of all ages and stages of life."

RN will be connected to the existing Google Health patient management application. As with many other applications integrated with Google Health, users can choose to share data from their Google Health profiles with the RN application. Researchers

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programming specification is being written, to begin software development.

The researcher network (RN) will be connected to the existing Google Health patient management application. As with many other applications integrated with Google Health, users can choose to share data from their Google Health profiles with the RN application.

Researchers participating in RN will have a unique opportunity to access anonymous aggregate information from patients who explicitly opt in. Patients can also choose to fully disclose their identities within the RN application and be available for interviews with researchers, discussions, patient education web meetings or pre-trial design meetings.

The vision of building a robust researcher–patient virtual community working together is now coming into focus.

The leadership and enthusiasm of Google Health Product Manger, Roni Zeiger was instrumental in gaining approval of the grant. We are grateful to Roni for all his assistance and continuing support of the project.

So, with this project we begin the development process of creating an engaging, dynamic researcher–patient community working together to discover PSC therapies, standards of care, disease management methods and accelerated research studies, to bring the day there is a cure for PSC closer.

participating in RN will have a unique opportunity to access anonymous aggregate information from patients who explicitly opt in. Patients can also choose to fully disclose their identities within the RN application and be available for interviews with researchers, discussions or pre trial design meetings.

“We are excited to be working with PSC Partners on the Researcher Network. This project will be an innovative use of Google Health to contribute to the acceleration of drug development therapies for patients with rare diseases,” said, Roni Zeiger, MD, Product Manager for Google Health.

Google will be partnering closely with PSC Partners during the development of the network, lending valuable technical assistance and insights.

The project work will be performed by a unique partnership of the Informatics department at UC Davis, where graduate students will work together with programmers from health informatics developer, Mt. Tabor Software of Portland, Oregon.

PSC Partners sees this application as the next step in moving the research and PSC development process ahead, faster, with a higher quality of statistical and patient information to bring the day of a cure that much sooner.

Spring Forward

by Ricky Safer, President, PSC Partners Seeking a Cure

As I’m preparing to set my clocks an hour ahead this weekend, I am already anticipating the arrival of spring with all its promise: warm sunshine and that wonderful fresh scent of blooming flowers and trees. In our “garden” at

PSC Partners Seeking a Cure, things are blooming as well. Our new website is reaching out to PSCers, physicians and researchers worldwide, our annual conference is approaching, and we have two new exciting

research opportunities. We are entering a season of great hope.

If you haven't already had a chance to check out our revised and redesigned website, take a look at www.pscpartners.org. It is unique because it features patient-centered content aimed at addressing the quality of life issues raised by living with PSC.

The site was prepared from the patient's point of view and was written completely by our knowledgeable volunteers. A new feature is the Ask a Pharmacist button. David Rhodes' amazing PSC Literature Site is still the keystone of our website. While you're perusing the site, be sure to sign up for our mailing list so that you can remain updated on all of our programs and research advances.

PSC Partners Receives \$50,000 Grant

We have just taken a huge step towards accelerating the pace of PSC research. I am very excited to announce that we received a grant of \$50,000 from the Google Foundation to build a PSC Researcher-Patient Network (RN) to hasten the development of PSC therapies, treatments, and standards of care.

The RN software will be designed to assist researchers in identifying new PSC patients, registering them, and recruiting them for studies. In addition, patients will be able to receive the latest information on research, and participate in educational virtual seminars led by recognized PSC researchers.

RN will be connected to the existing Google Health patient management application. To learn more about this project and other patient registry information, please read Tom Hill's article on page 1 and Rachel Gomel's article on page 7. A

huge thank you to Tom Hill, Consultant in Collaborative Informatics and to Dr. Chris Bowlus, Associate Professor of Gastroenterology and Hepatology and internationally recognized PSC researcher from the University of California Davis, who together put together this project, and also to Google Health for funding this project.

PSC Partners Has Matching Donor

We also have a very unique opportunity for you all to be part of supporting further research for PSC. Just recently, an anonymous donor contacted us and made an incredible promise: to match dollar for dollar the first \$100,000 that our members are able to raise (for our Itching for a Cure/Road to Connecticut fundraiser)!!

This fundraiser raises money to support PSC research. We can't let this unprecedented opportunity slip by, so please go to <http://www.pscpartners.org/fundraisers> to learn how you can help us succeed in this fundraising challenge.

If everybody does their part to help us raise \$100,000 before our annual conference (May 14-16), this amount will be doubled, and we'll be on our way to supporting \$0.5 million in PSC research projects. As of the end of 2009, PSC Partners Seeking a Cure is proud to be supporting \$317,706 in research grants. Please check out Sandi's article on page 11.

Annual Conference

Springtime at PSC Partners Seeking a Cure always signals our upcoming conference. If you can join us in Hartford, Connecticut, the weekend of May 14-16 for our sixth annual conference for PSCers and caregivers, please register now for what is shaping up to be a fantastic weekend for all attendees. We have a varied educational

agenda with speakers from The Liver Center at Yale University School of Medicine and several Hartford hospitals.

As always, there will be many opportunities to meet other PSCers and caregivers to share questions, concerns, experiences and advice. During the weekend, we share laughs and tears, and everyone goes home with a network of understanding friends as well as renewed confidence for handling life with PSC.

I have been working with Reggie and Jeff Belmont, the 2010 conference co-hosts, and we have added some new features to the weekend this year:

- On Friday afternoon, we'll have an interactive session on Healthy Living Choices: An Introduction to Complementary Therapies. Attendees are invited to come in casual workout clothes and experience a short introduction to a choice of stress-lessening activities such as yoga, laughter yoga, meditation and massage. We will also offer a session on setting up an individual exercise program.
- On Saturday morning, we have a session where speakers will give us an updated overview of PSC research worldwide.
- On Saturday afternoon, attendees will be able to attend three breakout sessions of their choice, chosen from a wide variety of topics and speakers.
- We are offering a PSC teenager group for the first time this year, if we have attendees in that age range.
- We are offering the option to register online and to pay registration fees online via PayPal (<http://www.pscpartners.org/register2010>).

To learn about conference details, click on: <http://www.pscpartners.org/nextannual>.

And to register, click on:

<http://www.pscpartners.org/register2010>.

Please register for the conference and reserve your hotel rooms as soon as possible. Remember these two important deadlines:

- Standard conference fees are in place if you register BEFORE APRIL 12. After April 12, late fees will apply.
- The hotel cutoff date for rooms at our discounted group rate is APRIL 23, or when our block of rooms has been filled, whichever comes first.

If you have any questions, feel free to write to me at contactus@pscpartners.org or to Reggie and Jeff at ctpsc@hotmail.com.

If you are a conference first-timer, here are several suggestions for you:

- Read the conference FAQ sheet: <http://www.pscpartners.org/register2010>
- When you fill out your registration form, request a mentor.
- Read Sandi's article on page 13, explaining the advantages of attending our conferences.

I know that the thought of attending your first PSC conference can be daunting and even scary, but please know that you will be welcomed into the PSC family the minute you arrive.

I'd like to thank our 2010 conference sponsors for their generous support:

PREMIUM PLATINUM SPONSORS:

Abe and Rachel Gomel

Illinois Tool Works

GOLD LEVEL SPONSORS:

The Liver Center at Yale University School of Medicine

Don and Ricky Safer

Jeff and Reggie Belmont

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Jason Drasner
Theresa Shanks

Don and I are eagerly awaiting the start of the 2010 conference. We're looking forward to learning the newest information on all aspects of PSC and to renewing old friendships and meeting all the new attendees. It's difficult to describe the positive energy and personal compassion of our group, so if you can attend the conference, sign up now!

Please join us in our efforts to spring forward

with our mission goals: to educate and support PSCers and their families, to raise money for PSC research, and to raise awareness of PSC and organ donation. Come to the May conference, help us meet our Itching for a Cure/Road to Connecticut fundraising challenge, or volunteer for one of our many programs. We appreciate everyone's help. Together in the fight, whatever it takes!

Ricky Safer
President

Illinois Tool Works – A Model of Corporate Cooperation and Compassion

For the second successive year, you will notice the name "ITW" as a major sponsor of the PSC conference. Why, you may ask, would a company that makes tools and machines, be interested in a meeting of people with liver disease?

The answer is that many companies like to "look after their own" and support endeavors that are close to their workers' hearts.

So though it might appear to be a waste of time asking for funding from your workplace, if the request comes from you,

an employee, the answer may surprise you!

ITW, Illinois Tool Works, is a particularly good example of corporate philanthropy in action. As a company, their "official" focus is in supporting the United Way and Junior Achievement, and this they do each year with enormous commitment and enthusiasm.

However, at the specific request of a PSC family, they also supported the 2009 conference at the gold level (\$5000). This year their \$10,000, platinum level gift will sponsor the Friday evening reception and audiovisual costs for the weekend.

Furthermore, ITW has a particularly generous matching gift program (\$3 on every \$1 given) which honors the more general fundraising interests of its people and boosts the proceeds of those yard sales and sponsored walks. Many companies offer similar programs.

Not all employers are as generous as ITW, and we are enormously indebted to them, but it makes us realize that there are available funds out there, however small, and hopefully we can all work together to make it happen. So whether you work for *Microsoft* or *Mom and Pop's Bakery*, maybe all you have to do is ask?

Report on the 2010 NIH Workshop on Rare Diseases, Washington, DC

By Rachel Gomel

Editor's note: See related article on Google's involvement with PSC registries, pages 1 and 2.

More than 400 people participated in a National Institutes of Health (NIH) workshop designed to explore ways of optimizing the exchange of information on rare diseases. *Advancing Rare Disease Research: The Intersection of Patient Registries, Biospecimen Repositories and Clinical Data* was organized by NIH's Office of Rare Diseases Research (ORDR) and took place in Bethesda, MD, on January 11th and 12th. The long list of people waiting for cancellations in order to participate, signaled the immediacy of the topic and the excitement it elicited.

I was there to gather as much information as I could about the US and international registry landscape and its potential for PSC Partners. The attendees included NIH and government policy representatives who advocated the integration of rare disease registries, researchers who were already using patient-driven registries and genetic repositories, clinicians who had created their own rare disease registries and who sought ways of enlarging, solidifying, and standardizing their registries, and most importantly, the patient/caregiver rare disease advocacy groups that either had functioning registries or that wanted to start their own registries.

This last group, mostly consisting of parents, was the most passionate, the most unified, and the most vocal. Through their powerful presence and constructive recommendations, they seemed to sway the general direction of the discussions.

Genetic Alliance

The day before, a registry "boot camp," led by

Genetic Alliance, a rare disease advocacy group, served as an excellent introduction to the next two days. The boot camp was a powerful expression of the importance of having a patient-advocacy-group-directed registry that facilitates the dissemination of information among patients, clinicians, and researchers seeking otherwise difficult to find data.

The boot camp elicited much excitement in me as I saw our PSC Partners' readiness to embrace such a registry, thanks to its established slate of participants consisting of its own membership, and our active, highly knowledgeable and responsive Yahoo support group. It was equally exhilarating to hear about the advances in research and the powerful presence that such registries have been enabling.

Among the successful patient/parent run rare-disease advocacy groups at the NIH meeting, Genetic Alliance was presented as an important example and model for creating a successful advocacy group. As a grass roots group like our own PSC Partners, Genetic Alliance first started in 1986 as a foundation, when Sharon Terry's two children were diagnosed with the rare disease PXE (Pseudoxanthoma elasticum, relating to mineralization of the skin and other areas of the body).

Sharon and her husband created a patient advocacy group for this rare disease, and led the research that recently culminated in the discovery of the PXE gene. Sharon's philosophy of cooperation and of partnering with other rare diseases led to the creation of Genetic Alliance,

which is now at the forefront of consumer participation in genetics research, services, and policy. Like many of the advocacy groups that were present at the meeting, and like NIH's ORDR and National Organization of Rare Diseases (NORD), Genetic Alliance reflected on the importance of joining forces with other rare disease groups.

Genetic Alliance's stated mission is that of empowerment through partnerships, to "eliminate obstacles and limitations to finding solutions to rare diseases through novel partnerships including disease-specific advocacy organizations, universities, companies, government agencies, and policy organizations."

And are they ever meeting their goals with great success! Their network, consisting of myriads of organizations, provides an open space for shared resources and creative tools. They formed a consortium of seven rare-disease advocacy groups. They receive seven federal grants totaling \$12 million over five years, and their loud voice is extremely well heard.

New Science

The sessions were filled with statements that reflected the "new science" and the shift in approach to rare disease: "The silo approach has failed," they said, referring to the compartmentalized practice in traditional medicine, where each disease is studied as a separate entity. "Every disease is a rare disease; each human being is a rare disease," they said. "When molecularly classified, all disease is rare." "Historically, progress has been made in disease-specific silos, and often the lessons learned are never shared with the community at large. This impedes the development of better health and research... Since sequencing the human genome, we know that there are gene

families, pathways, and other more effective ways to understand disease... Now is the time to strengthen our collaborations... We call for a culture shift in the relationship between advocacy, research, services, and policy..."

The buzz words were partnership, sharing, and participation: patients partnering with researchers to advance research, registries partnering with other registries, and researchers, clinicians, and patients partnering with government agencies and academic institutions, and other such permutations of collaboration.

Patient groups were urged to incentivize physicians and clinicians to contribute data to registries and tissue repositories. The head of NIH's ORDR, Stephen Groft, proposed that centers of excellence for physicians be identified to stimulate such participation, and others added that such recognition would prevent hoarding of information for advancement purposes by physicians, researchers, or academic institutions.

Specialists discussed how to develop a standardized vocabulary that could serve as an effective interface among rare disease registries. Much effort is being spent on creating a common language of communication, so that the information on one registry can be translated to that of another rare disease registry. The goal is to make intersections and commonalities between diseases easily detectable.

It was exciting to see the commitment of NIH's ORDR, NORD, and other agencies and academic institutions offering their help in creating registries and advancing rare disease research.

Rare Disease/Common Disease

Another recurrent theme in the conference was the importance of linking rare diseases to

common diseases. The clinicians felt that rare diseases had much to teach about common diseases and that such links would make research of rare diseases more inviting. Genetic Alliance's growing consortium of rare diseases revealed the feasibility of such associations and the favorable outcomes such unions can create.

The feeling was that rare disease groups could carve themselves a powerful place within the medical world. The more rare and the more serious the disease, they said, the more powerful and effective the advocacy group has proven to be. Consequently, many parent/patient-led initiatives have faster and more solid outcomes. In the case of rare disease groups with registries, pharmaceutical companies, for example, haven't needed to stop trials due to lack of patients. Patient groups have special plugs, they said. The message was loud and clear: there is strength in numbers, and unity is critical.

Successes

Examples of success in the rare disease arena abounded. One most moving story was Leslie Gordon's. She is a mom, a physician, a researcher, and Brown University professor. Thirteen years ago, her child was diagnosed with Progeria, a debilitating disease in which children grow old by the minute and die of a heart attack in their early teens.

Leslie started a foundation and a registry for Progeria. As there are only a handful of Progeria patients in the US, she sought them out throughout the world and was able to gather 82 participants for the registry she created. Through partnerships with Rhode Island Hospital, Brown, Genetic Alliance, and a pharmaceutical company, she and her team funded 27 research projects, ran 5 scientific meetings and discovered the gene mutation for Progeria. The disease was redefined

through publications, information from their tissue bank, and neurovascular studies. Thanks to their registry, they have recruited for medical trials at lightning speed. Interestingly, they work with heart disease groups and have gained support from groups focusing on this common disease. Her foundation raises a million dollars each year.

Another such example of a successful advocacy group was the Susan Love Research Foundation for breast cancer. Dr. Love's approach was fascinating in that it was based on the premises of the new science: breast cancer is not a single disease but many different diseases. Male breast cancer is different from a young woman's or an older woman's breast cancer. Dr. Love treats breast cancer as a series of subgroups of rare diseases. Her approach is opposite to common research practices of collecting samples from patients with a given disease and reflects her conviction that there is no difference between rare and common diseases.

Based on the high number of people that have risk factors for breast cancer, she introduced an open registry concept, inviting anyone with or without breast cancer to participate in medical trials. The foundation broadcasts *what* they want *when* they need it, and through newspaper and TV ads, recently they recruited 5000 people within five hours for a single study. I came out thinking that there was no single formula for success, and that disease context would have to guide the kind of advocacy group that each rare disease group needed.

Future Registry Relationships

Some of the government agencies that were present at the meeting supported an uber registry, a term that was coined during the meeting by one of the vocal critics of the government's proposal

to integrate all rare disease registries, and that was subsequently used during the two days.

The patient advocacy groups rejected the idea of an uber registry, and instead, argued on the benefits of moving towards a registry of registries so that the unique nature and needs of each separate disease would not be lost in the heap. A registry of registries, they said, would facilitate the search for intersections and similarities among rare diseases and would change the landscape of clinical trials and treatments.

It was agreed that it was important for advocacy groups to maintain ownership of their respective registries, bring to light every nuance of their rare disease and stimulate research through the partnerships they created. It was clear that registries were at the cottage industry stage and that critical partnerships would be key at this point in time.

The three days, filled with back-to-back presentations (28 on Monday!) did more than

offer a rich forum for discussion. Behind every idea that was introduced, there was a powerful success story told by one or several patient advocacy groups. The stories made us cry, contemplate on the speed at which rare disease groups could turn ideas into action, and experience the power of acting in unison. I felt that much of what was discussed during these sessions had a huge potential to become reality. Groups were eager to share information and NIH's ORDR and other agencies seemed to be incredibly receptive to new ideas and were committed to helping.

Excited by the spirit that united this massive audience, I could feel the power of our own togetherness at PSC Partners and thought about the enormous new possibilities we had been introduced to and could embrace together.

A website regarding the conference is at: <http://rarediseases.info.nih.gov/ScientificConferences.aspx?ID=1021>. Click on "Other Materials."



See You At The 2010 Conference of PSC Partners Seeking a Cure!

We're taking over Hartford, Connecticut, the weekend of May 14-16 for another of our famous gatherings to learn, support, and have fun with almost 200 PSCers from the US and around the world. PSCers of all ages and stages will be there (caregivers, too!) and you won't want to miss this amazing experience.

- Take advantage of early registrations savings! Don't delay!
- Check the agenda and find out other information here: <http://www.pscpartners.org/nextannual>.
- The PayPal payment option is available for the first time this year and you can register online if you wish. Here's the site: <http://www.pscpartners.org/register2010>.



Itching for a Cure

**Road to Connecticut
Fundraising Challenge**
PSC Partners Seeking a Cure

Get Your Motors Running: Itching For A Cure/ Road To Connecticut \$100,000 Matching Donation Fundraising Challenge

by Sandi Pearlman

We all love a good road trip, the tunes, the food—the funds.

That's right, the funds, because right now PSC Partners is offering up the biggest, the boldest, the best road trip to date!

Those of you who have been with us for a bit know that as each conference rolls around, we travel the virtual highway from conference locale to conference locale translating miles to money so we can race towards a finish line that includes better treatments and a possible cure for PSC. This year though, we've got the pedal to the metal and an anonymous donor who's painted

the racing stripes on our cars and highlighted that checkered flag with even more temptation than ever!

Gone is the miles for money approach. Instead, we're playing for progress.

Each time we enter into one of these cities: Detroit, Pittsburgh, Buffalo, New York City and New Haven on our path from Chicago to Hartford, our anonymous donor will donate \$15,000 towards our cause. And nope, you didn't read that wrong that's \$15 grand, buckaroos. That's pure bread, honey!

And grand doesn't even begin to touch what he or she is offering if we can make it from New Haven to Hartford where the conference is held.

I'd tell you all to guess, but our donor's generosity is so flooring I'm just hoping you're sitting down when I tell you. The last few miles of our road trip, crossing into Hartford, generates another \$25K! That's \$100,000 from our amazingly fabulous gift from the heavens, make me believe in karma and that pennies do always land heads-side up anonymous donor!

So, how do we take advantage of his or her AMAZING generosity? Well, we get involved and we get involved now! So, buckle up your seatbelt, grab your sunglasses and strap yourself in 'cause we're racing to the finish line and there's nary a red light in sight!

Every single dollar amount counts and makes a real difference. Raid your change drawer, donate your tax refunds. Ask for donations to be made to Road To Connecticut (RTC) in your name in lieu of gifts. Call your neighbors and the PTA and hit up those coworkers in the name of a good (tax-deductible) cause! You can hold a fundraiser. Send a check. Fill a coffee tin with coins and

mail it to us. However you choose to make a difference can and will help!

For those of you who'd like to put your internet inbox and address books to work and need some help formulating a sample letter explaining RTC, contact me, Sandi Pearlman @ Kizzersmom@yahoo.com or Lee Bria @ Leedeubert@gmail.com and we'll be happy to share some sample letters that you can then send to your friends and family requesting their help and generous donations either through snail mail or via the internet.

Every time we as a group earn \$15,000, we've reached a new city limit and the anonymous donor matches us making racing down the road toward a PSC cure all that much more sweet.

We've already cruised to Detroit and while we were be-bopping along to some Motown and showing off some rather groovy dance moves behind the wheel, the matching money was put in! Next stop is Pittsburgh, so whether you're leaning more towards the Andy Warhol Museum or heading towards the Steelers' stomping grounds, get those donations flowing!

If you've ever wanted to make a difference and be a real part of finding and funding a cure for PSC, the timing couldn't be better to put yourself into the driver's seat no matter your age, schedule, or income. With our anonymous pace car hero offering \$100,000 in a dollar for dollar match, we've got nothing but blue skies, clear lanes and not a single stop sign in sight!

Please, join us on the Road to Connecticut today, because road tripping just isn't as much fun unless we're all traveling the trails to tomorrow together and if you find yourself humming a driving song or two, I'd suggest "Life is a Highway," because with RTC funds going

directly towards research, well, we'll want to drive that baby "all night long!"

To get behind the wheel and donate right now, send a check to:

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

Or pay by credit card via Paypal @ <http://www.pscpartners.org/fundraisers#itching>

Please:

1. Earmark your donation for the Itching for a Cure/Road to Connecticut fundraiser.
2. If your donation is in honor or in memory of someone with PSC, include the honoree's name and address, so that we can send them or their loved ones an acknowledgement of your contribution.
3. Include your email address.

Funds raised to date: \$24,094 (early March, 2010). Matching funds to be added by our anonymous donor to date: \$15,000.

Use this link to view our progress on the RTC map:

<http://www.pscpartners.org/fundraisers#itching>

To register for our 2010 conference (May 14-16):

<http://www.pscpartners.org/register2010>

Research in inflammatory bowel diseases (IBD) is changing and improving the way Crohn's disease and ulcerative colitis are diagnosed and treated.

On Tuesday, March 30, at 1:00 pm ET (Noon CT/ 10:00 am PT) tune in to a Crohn's & Colitis Foundation interactive educational webcast/ teleconference, "Breakthroughs in IBD Research: Helping You Today."

[Register for this event today!](#)

Editor's note: Sandi's article below presents a baker's dozen of reasons to attend the annual conference in May--the personal and human connections one makes at the meeting will last long after the event.

But if you can't make the Hartford meeting, you can still tune into the excellent presentations in two ways. First is through our website, where we include the Powerpoint slides from sessions. Here is the site URL with conference slides since 2005: <http://www.pscpartners.org/prevannual>. The 2010 meeting slides should be up by mid-summer. Second, we offer summaries of each presentation in our Summer newsletter.

20-30 Somethings

The Top Ten* Reasons to Attend the 2010 PSC Partners Conference

by Sandi Pearlman

Everywhere I look lately, it's all about lists. There are books about making lists on the bestseller list (which further proves my point.) Commercials on TV remind me not to miss Dave's Top 10 list. Even the memo pad on my fridge begins with the words "Things to Do:" followed by a series of blank lines and numbers. So, although I usually dedicate this column to the worries, woes and triumphs of the 20s/30s set, I give in. I got the message. With no further ado, here it is: The PSCers (20s/30s) Top 10* Reasons to Attend a PSC Partners Conference

1. **Know you're not alone**

So, the doc says, "Surprise, you have PSC. It's this rare, incurable..." and, well, there were probably more words but you were too stunned to hear them. Since that time, if you're lucky, you've met other PSCers, connected at PSC Partners support groups and attended some or all of our conferences. If you're not that lucky, good news is it's an easy change to make! Isolation is one of the worst parts of having a rare, chronic illness that even doctors have to ask you to

repeat the name of, let alone your closest friends and family members. It can be incredibly hard to be the only one in a group with constant itching or the sound of sand running through an hourglass whooshing in your ear. Too many of us feel all alone and are stuck having to wonder if what we go through is normal. Do we know all the facts? Does our doctor know all the facts? What does PSC mean for my life and my future? One of the most amazing things about a PSC Partners Conference is finding out just how not all alone you are.

2. **Experience the joy and hope**

You'd think that a conference all about PSC would be at best heartbreaking and depressing and at worst invoke heretofore undiscovered suicidal tendencies. The truth is nothing could be further from the truth! Yes, it's a conference about a rare disease with which we all suffer. Experts go over the latest news in research and education. We hear some tough stuff. There are moments where tears are not out of line. However, mostly, those tears are running down

your face from laughing so hard you start to worry about peeing your pants again like when your best pal shot chocolate milk out of her nose in elementary school. Don't ask me how we manage it, but the three most prevalent things in any PSC Partners conference are joy, hope and laughter.

3. **Become informed**

The internet is full of scary "facts" as are, sadly, some physicians woefully unfamiliar with PSC. First and foremost, PSC is not a death sentence completely devoid of any hope. Not only will you hear from experts in different fields about the latest in PSC research, education and awareness, you'll actually be in a room with PSCers who are living happy, normal (or at least relatively normal) lives. You'll see firsthand that PSC doesn't mean Person Scared Constantly and that alone is worth the price of admission!

4. **Be a part of the "in" crowd**

In our daily lives, we're the other. We're the ones with the ticking time bomb in our livers, the need to go to bed before most 9 year olds we know, the ones who stutter when asked how we are and have to debate whether the question is sincere or merely perfunctory and wonder if the person asking could even handle the truth. At a PSC Partners conference though, we're the normal. Those caregivers and siblings and friends, they're the ones out of the ordinary. I mean, not taking a single medication? How odd! Eating without pondering what it means to their systems? Not having to know where the nearest bathroom is at all times? Completely peculiar! In fact, some of our caregiver attendees in the past have been so jealous that they're not at the popular kids' table, they've even coined themselves a phrase. We might be the PSCers, but they're the PSCEers*. A little sick (no pun

intended), yes. Funny and kind of fab to be in the envied group even just for a bit...well, heck yeah!

5. **Scratch, itch, nap in peace**

Have you ever been sitting in a classroom or a meeting or a dinner party or anywhere and simply dying to scratch yourself...and I don't mean a quick ten-second thing, but a full-on make like a bear and rub against a tree to relieve the itch kind of a thing? Well, at work you're bound to freak people out. In class, they'd definitely notice. At the movies, they're calling security and at a dinner party, well, let's just say nobody's going to be wanting to hug you goodnight or invite you back.

At a PSC conference though, you can itch and scratch and do so right out in the open without a single bit of self-consciousness. Embarrassed that you always seem to itch in non-public appropriate places (such as armpits, chest, um, God-given goodies), not only can you complain about it out loud, you'll find you're not the only one, and maybe even learn a covert method or two for scratching there without attracting notice. Caveat: Never ever do those things on a first date or a job interview if at all possible!

Need a nap to make it through a day? Want to go to bed at 7 p.m.? Well, go right ahead. No judgments here. In fact, we've long talked about the fact that pajamas as a daily-living requirement should be totally accepted (and not just by high-school cheerleaders). In fact, a pal and I even created a group for it: NAPS* Don't you sometimes think life would be so much less complicated if you were already in your jammies when the exhaustion hits?

6. **Make lifelong friends**

A PSCer pal of mine once told me that she feels that our conferences are like getting together with your very best friends--albeit the ones you might only get to actually see once a year. I can totally relate to that. There's no need to hide anything at these conferences. Seriously, you will NEVER find a more accepting group of people. Even things you're afraid to admit out loud to yourself are perfectly acceptable to bring up at the conference.

Not only will you most likely find that you're not the only one with whatever the particular issue is, but probably, you'll find commiseration and perhaps even some laughter and help to go along with it. Nothing is off limits for us. Want to discuss why your stools float, go for it. Want to complain that your gas or burps smell like rotten eggs, we've heard it before. Want to know if anyone else has to cut every single tag out of every piece of clothing they own just to get some itch relief? Well, I'll bet you dollars to donuts you find at least 30 people who are on board with that!

Further, bonds created at the conference last. We may not get to see each other physically very often since we come from, literally, all over the world, although occasionally just down the block as well, but we Skype. We chat and text. We FB. Our bonds are strengthened and lifelong. We can talk about PSC symptoms as easily as we talk about True Blood or our sad but unending love for Buffy the Vampire Slayer (despite having ended years ago) or Glee or how Thai food is so much better than Chinese. We can go for months without talking and still know 100% that our PSC pals love us and have our backs and vice versa. Where else can you walk into a room feeling perhaps a little uncomfortable or a lot nervous and be pretty darn assured that you'll come out with friends for life?

7. **Get practical tips to improve your daily life**

Got a question? Chances are, we've got an answer. Want to know if sweating or acne can be a part of PSC? (Unfortunately, yes.) Even better, want to know what other PSCers have tried and found either to work or not work? No problem, we're there to share. Think your medical team gave you bad advice? Ask if anyone else has heard the same thing and/or how they were able to talk to

An Advocate for Managing Through Chronic Illness

Author Jennifer Jaffe, Esq., who compiled the book, *It's Too Hard to Be Sick in America: Stories of Chronic Illness*, which is free on the website below, was a speaker at our conference in Chicago last year. She covered health insurance and employment rights.

Ms. Jaffe is Executive Director of Advocacy for Patients with Chronic Illness, Inc., which assists patients with their legal rights on a wide range of issues.

As founder of the organization and as a chronic disease patient herself (Crohn's and gastroparesis, to name but a few health issues), she has dedicated herself to taking on the bureaucracies of government, insurance, education, and employment to assist patients and caregivers like us become our own advocates.

Check her website:

<http://www.advocacyforpatients.org/index.php>

their doctors to make things better. Learn about different diets and lotions and medications and whatnot that make a daily difference in the lives of so many of us. Feel like you can't date or join your pals at a club because it's awkward to answer "what do you do" questions or be the only one not drinking? Wondering how others told their kids, bosses, pals, prospective life partners, etc., about PSC. Well, the answers are all just a conference away.

8. **Find the meaning:
Learn how to make a
difference in your own
life and other PSCers'
lives if you so choose**

Ever wonder "why me?" Want to know what you can do to further the cause? Want to find out how easy it is to hold a fundraiser to raise awareness and money towards a cure and better treatments? Want to have complete and total proof that you're not all alone in this? If you answered yes to even one of those questions, you guessed it, the conference is the place for you!

9. **To be with people of
your own age who like
to, want to, or have to . . .**

Well, you name it: Party, drink, date, be intimate/

romantic, wonder about fertility, worry about what PSC means for procreation, figure out how to tell someone, wonder if children can be a part of their future, want to know when not telling crosses the line from privacy to deceit. Is taking a drink really endangering your life and liver with every sip? Can you drink wine but not beer? Is a little blue pill in your future? Can female PSCers get pregnant and carry to term? Can we still feel attractive and deserving of love and marriage? Are we lying if we don't tell our bosses what's going on or mention it on a job interview when asked if we have anything we'd like to say or what our weakest points are?

The point is you'll be in a room with people who worry and wonder about those same exact things. Instead of getting one view from one person, you can get 20 different views; you can find one that makes sense to you. You can have your fears allayed. And, well, for those of you who are single and looking, can I just say that we really are an extraordinarily attractive group of people!

10. **Put an actual face to all
your FB friends**

Come on, admit it. You're really curious about some of

your FB PSC pals. What better chance than this to actually check them out and see what they're really all about!

11. **To allow your parents or caretakers to talk with other people similarly situated so they don't keep asking you the same questions or saying "I don't understand" or look at you like you're nutso or seriously disturbed when you say you'd cut your own feet off to stop the itch?**

We all know it, the pitying look we get from our friends and loved ones (and sometimes complete strangers in the grocery line or church or wherever), that look that makes you want to scream. We try to describe what it's like to live with PSC to our friends and family but realize that they'll never be able to understand, even with the spoon theory.* I'm more than a little ashamed to say I've broken out into a full-blown tantrum when my father, thinking he's being helpful, asks me to rate my pain on a scale of 1 to 10. I know another PSCer who says he simply can't get a day free of his mother asking him if he pooped and what color it was and whether or not blood was

present. I've also got to say that I feel enormous guilt at times about the stress and strain my illness has put on my family and friends. I worry they spend all their time worrying about and taking care of me and forget to replenish and spoil themselves. I'm scared they live in denial. I'm impatient when they don't know a medical term that's second nature to me (because we all know that PSC comes with a whole new vocabulary, free of charge).

The thing is I'll never know what it's like to be a caretaker of a PSCer, at least, I sure hope not. Our parents, sisters, brothers, lovers, pals, relatives, etc., are dealing with watching us go through something where they can't really tangibly help at the end of the day. They can't make our livers behave or our pain disappear. They can't stop the vomiting or help us think straight when encephalopathy sets in. They can't, much as they would like to, have our transplants and treatments and ERCPs and the like for us. They need to talk about this. They need somebody else to reach out and hold their hand and tell them they get it, and really, truly know that they each know what the other is going through.

It's not just the PSCer that is oftentimes isolated by the disease. It's all those who love us. The conference is a great gift to them to be able to find support and to hear the truth and experience the feeling of being in a room full of PSCers who are so much more focused on laughter, joy, friendship and hugging than death and dying. They need to be able to look into each other's eyes and cry and feel what they feel without worrying about putting too much on us. We need to give them that gift, not only for them, but for ourselves too.

Is a Transplant in Your Future?

Learn what to expect--from those who've gone through transplant already. The highs, the lows, what to ask, how to cope.

At the conference we'll present two panels that include patients who've received transplants and can give you the skinny.

12. To see who can make up the most memorable and useful phrases using only the letters "PSC"

Okay. I'll admit, this might not seem like a reason to come to a conference, but that's only because you don't understand how delightfully fun and distracting this game can be. Go on, give it a try...you know you're dying to give it a go! Here are some of my favorites from years past (some mine, some belonged to others...and those of you who they belonged to, sorry if I don't give you name credit..but I truly can't remember anymore at this point who said what.)

Pee Speed Champion --this one was attributed to our own PSC Partners' President by one of the funniest and most fabulous ladies you all will ever meet who happened to be in a stall next to our fearless leader one conference afternoon. (Seriously, meeting Sheller and Ricky and Don and the rest of the gang should count as a reason to attend the conference; you'll get it once you get to know them!).

In any case, the list continues: Princesses Sleeping Contentedly,

Please Send Cure, Pretty Suave Chicos, Please Send Chocolate, Pretty Scary Concentration, Patient Spending Club, Peas Sauerkraut Chicken --I'll admit this one makes no sense to me, but I love how if you say it with the right intonation it sorta sounds like a curse! :)

Anyhow, you all get the idea. . .

13. **To better realize that having PSC does not mean that your life is over, but instead offers you the opportunity to explore alternative choices**

Less than ten years ago, I'd have never guessed that I'd be living a life where I'd be listed as permanently disabled and be unable to work, where driving a car is only a distant memory and that I would have my own shelf in my local pharmacy.

Less than ten years ago, I was worried about whether my boss liked me, if I looked fat in things and what strangers on the subway were thinking when they saw me (and why they felt it was okay to touch me in places even past loves

hadn't ventured). I presumed my friends and confidantes would be there for me come what may and that nothing could shake those bonds of friendship.

Then, I got sick. I lost my job. Many of those "forever" friends wrote me off and haven't talked to me since, because of fear or lack of interest, I'll never know. I was feeling miserable, truly miserable and useless and like I didn't have a purpose in the world.

Basically, I was counting breaths until it was time to die. I wasn't actively pursuing death, mind you, just figuring it was quick on its way thanks to the ruins of all the things I thought I might have become.

These days, I get accused of thinking the glass is so full that it's slopping over the sides and that it's the size of a 10-gallon rain barrel. Polyanna* has nothing on me. It's not that I don't get down or blue, er, yellow, I guess is more accurate for us. It's that I'm able to see the forest for the trees. And I'm guessing you'll think this is cliched, but want to know why I'm largely sunshine and pink tulips? You guessed it, I went to a PSC Partners conference.

Your Diet: Can it be Improved?

How does diet affect how you feel? Are you getting the right nutrition? Can your diet affect the progress of PSC? What about supplements?

At the conference, check out the presentation from Erin Paice, Certified Dietician, Registered Dietician-Nutritionist, Transplant Dietician, on the role of nutrition in PSC.

I'll tell you the truth. I didn't want to go. I couldn't stand the thought of being stuck in a room with a bunch of sick people and talking nonstop about feeling terrible and all the rest. I wanted to hide under the covers and cry. Instead, I got out of the car and ran into Ricky and Don Safer about one minute after I arrived. Ricky's the PSCer, but there she was practically sparkling with warmth and radiation and

buzzing with energy. Don had a mischievous twinkle in his eye and a hug and a grin that made me instantly feel safe and part of a family. I was still wary, but less so.

As the weekend wore on, I realized that warmth and sharing and frivolity made the hard stuff easier to bear and by the end of my time there, I truly had made lifelong friends and found a new purpose to my heretofore meaningless days.

I was part of something. I am a part of the PSC family. I'm part of an organization whose sole purpose is to have nothing left to fight for. We won't quit until we've cured PSC and made sure no PSCer ever feels isolated and alone again unless they so choose. We'll fight together, whatever it takes until the need for us is absolutely obsolete.

I tell everyone that attending the conferences is a game changer in the best possible way. I can. I know it to be true. I know it'll be true for you, too.

Footnotes:

•Per Sandi's Count: a system where the actual mathematical equivalent is irrelevant to the amount of words and topic headings posted.

* PSCE: A made-up condition for the well-meaning friends and family of PSCers. PSCE can either stand for Primary Sclerosing Cholangitis Envy or Primary Sclerosing Cholangitis Empathy. (Ex: A PSCer will claim PSCE when exhausted and needing a nap or whenever they itch.)

•NAPS: National Association of Pajamaniacs, a ridiculous group started just for fun and to spread my mission that Thanksgiving should be a pajamas-required holiday.

Come on, think about it, it really does make absolutely perfect sense, right? Find NAPS at: <http://www.facebook.com/group.php?gid=51621655217>)

• The Spoon Theory: a practical and easy to understand description of some of what life is like for the chronically ill <http://www.butyoudontlooksick.com/navigation/BYDLS-TheSpoonTheory.pdf>

•Polyanna: A movie starring Haley Mills (if you don't know who she is, don't tell me, it'll break my heart! Oh, and go rent the original Parent Trap immediately!) as a young girl who is exceedingly optimistic no matter what's going on around her.

To register for this year's conference and join the fun, go to: <http://www.pscpartners.org/register2010> . We can't wait to see you there! :))

A BIG Thank You to our Current Conference Sponsors!

We couldn't do it without our special conference sponsors!

Premier Sponsors: Abe and Rachel Gomel, Illinois Tool Works

Gold Level Sponsors: The Liver Center at Yale University School of Medicine, Don and Ricky Safer, Jeff and Reggie Belmont

Silver Level Sponsors: Ken and Patty Shepherd

Copper Level Sponsors: Jack Drasner, Theresa Shanks

There's still time to become a sponsor. Contact Ricky Safer. Via email at: contactus@pscpartners.org.
Via mail at: PSC Partners Seeking a Cure, 5237 So. Kenton Way, Englewood Colorado 80111.
Or by phone at: 303 771-5227.

Another Genetic Study of PSCers Announced: Consider Participating

Dr. Lazaridis at the Mayo Clinic/Rochester is calling for volunteers in a new type of genetic study that he is starting, based on experiences from IBD, where researchers will genetically characterize a large family with multiple family members with PSC. (It is a different type of study from the genome-wide association studies being done, and it could be an alternative way of finding disease genes in PSC. See below.)

If you are a PSCer and you have one or more family members with PSC, please consider participating in this study. To enroll or to learn

more about it, please contact Erik Schlicht, the study co-ordinator at Schlicht.Erik@mayo.edu or Dr. Lazaridis at Lazaridis.konstantinos@mayo.edu.

As a reminder, Dr. Lazaridis is still recruiting PSC patients without family history of PSC for his PROGRESS study. If you're interested in signing up for this study, go to our website (www.pscpartners.org), click on "Take Charge" and then on "Join a Current Trial."

Scroll down until you come to the discussion of the PROGRESS study. They already have enrolled close to 700 PSC patients so far, but they're still looking for more volunteers.

Please think about becoming a volunteer for one of these studies.

New Members of Scientific/Medical Advisory Committee Named

Doctors Keith Lindor and Johannes Hov will be joining the Scientific/Medical Advisory Committee to help us decide on PSC research priorities and help select the best proposals for future PSC research funding. Members of the PSC Partners Seeking a Cure board and scientific/medical advisory committee are listed here: <http://www.pscpartners.org/boardmembers>.

Dr. Lindor has published over 267 papers on PSC, PBC and other liver diseases (including nonalcoholic steatohepatitis; NASH): <http://www.psc-literature.org/LindorK.htm>.

Dr. Hov has been a research fellow at the Norwegian PSC research center (www.rikshospitalet.no/nopsc) in the Clinic for Specialized Medicine and Surgery at Oslo University Hospital Rikshospitalet, the only transplant center in Norway, since it was founded in 2007, and has a long term perspective on PSC research.

We believe that they will be very valuable members of the team!

Board Member Chris Klug Takes Donor Awareness to the 2010 Olympics

We tip our ski helmets to board member and snowboarder Chris Klug for his determined try at the Vancouver 2010 Olympics last month. Even though he didn't claim another medal, he's a gold medal winner to us!

He's a post-transplant PSCer and won a bronze medal in the 2002 games, just 18 months after receiving his new liver. His story has inspired PSCers and others to keep fighting, stay determined, keep going in the face of tough challenges. In Vancouver, he was fighting, among other things, rain, slush, fog, and sleet.

The Chris Klug Foundation (CKF) was launched after his July 2000 transplant and his Olympic win in 2002. CKF is dedicated to organ donor awareness. While in Vancouver he visited a hospital, met with a transplant support group, and generated publicity for organ donation. Many of his Donor Dudes fans cheered his runs down the mountain.

There's an article by Nate Peterson in *The Aspen Times*, Chris' hometown newspaper. Click on the link below if you wish to read the original article:

<http://www.aspentimes.com/article/20100227/OLYMPICS/100229796>.

For more information, or to get involved, visit the Chris Klug Foundation website at <http://www.chrisklugfoundation.org/> or contact Morgan Ilika at morgan@chrisklug.org. The Chris Klug Foundation is dedicated to promoting lifesaving donation and improving the quality of life for donors, donor families, organ transplant candidates and recipients.

Join our Mailing List or Easily Update Your Interests

If you want to stay up to date on news of PSC Partners, PSC research topics, events and other news vital to understanding PSC, be sure to join our mailing list. It's easy!

Sign up on our homepage: <http://www.pscpartners.org> in the upper left hand corner.

Already signed up? You can check and update your news interests, determining only the topics for which you want to receive notices.

Give Us a Hand

We're looking for a few good men and women.

We're looking for people to offer their time, talent, and caring to PSCers through PSC Partners Seeking a Cure.

If you'd like to volunteer with us, check this portion of our website to learn what projects we're looking for help with:

<http://www.pscpartners.org/opportunities>

Still interested?

Write to:

volunteers@pscpartners.org

New on Our Website: Ask a Pharmacist

We are pleased to offer this new option for PSCers and caregivers. A registered pharmacist is ready to answer your questions on side effects, drug interactions, the best way to take meds, working with your pharmacy (retail or mail order), the differences in generic and brand name

meds, dietary supplements, OTC meds (non-prescription, over-the-counter), patient assistance programs, possible new meds or formulations in the pipeline, and whatever else you want to know. Our pharmacist cannot prescribe and cannot answer questions about a specific case's dosages and medicines, so questions will be prescreened. Check it out on the homepage: <http://www.pscpartners.org>.

The Issue of Generic Drugs

by *Pauline, our website's Ask a Pharmacist*

PSC patients and post transplant patients find themselves taking a variety of prescription drugs during their journey with illness.

Two of the most common are ursodiol (originally marketed as Actigall®) during the progression of PSC and tacrolimus (originally marketed as Prograf®) after transplant.

Patients ask why they receive a generic when in the past they have been on the trade name product. Understandably insurance companies try to save money for patients and themselves. Co-pays are usually higher with brand name products than with generics. This issue will not be discussed at length here but

other factors to help patients direct their care will hopefully answer important questions and provide PSCers with a better background on this subject.

State Laws

State pharmacy laws differ regarding the substitution of a generic product when a trade name is written by the physician. First, I recommend patients check with a local pharmacy regarding state law.

To receive a brand name product your physician may need to write on your prescription a phrase such as "Brand Name Medically Necessary" or "No substitution" or "Dispense as Written." Any of these phrases

may prompt your pharmacy to fill your prescription with the original brand name product.

Therapeutic Index

Another factor which may affect generic tacrolimus dispensing is what is called "narrow therapeutic index designation."

Some states may rule tacrolimus as a "Narrow therapeutic Index Drug." This may not allow pharmacies dispensing in that state to dispense the generic when the trade name is written on the prescription.

What this phrase means is that the agencies in that state have reviewed evidence "exhibiting limited or erratic absorption, formulation-dependent

bioavailability and wide inpatient pharmacokinetic variability that requires blood level monitoring.” These agencies decide to give a drug this designation based on their opinions.

As most post-transplant PSCers know this drug does require regular monitoring and some patients do have difficulty maintaining the desired therapeutic range (the level his or her physician sets as a goal).

Changing from brand name product to a generic then to another generic and so on may complicate this process and make management of patient dose frustrating for both patient and provider.

The FDA does not support this action on a national level but as is the case with laws, the state level can always be more strict in their regulations than the federal level but may NOT, however, be more lenient than federal regulations.

A narrow therapeutic index does not necessarily mean a generic product cannot be used but the general rule of thumb is that changing from brand to

generic or from one generic to another requires close monitoring by physicians to assure both safety and efficacy.

Generic Testing

Another question asked by patients is, “How are generics tested?” There are agencies which determine standards for drugs before they become available on the market. The USP (United States Pharmacopeia) and the FDA (Food and Drug Administration) complement one another for this process.

The USP sets reference standards for the physical characteristics of a product. Quality and purity standards are established by collaborative testing by at least three independent labs. The FDA is the enforcer of standards determined by the USP.

Orange Book

Another tool used by the FDA is known as the Orange Book. Different states have regulations on substitution based on Orange Book ratings of products. The coding system involves the use of letters “A” and “B” and “X” and numbers.

A generic product has at least one letter and usually two. The purpose of these ratings is to convey to practitioners whether “bioequivalence has been established.”

For example an “A” rating means the product is considered by the FDA to be therapeutically equivalent to other pharmaceutically equivalent products. Another example is if a product has the rating “BX” this means bioequivalence has not been established and for drugs requiring a consistent blood level be maintained, such as tacrolimus, this would not be a generic product that should be substituted.

Within the past year the manufacturer of Prograf® challenged the FDA to test their product in transplant populations against the generic prior to release. This request was denied.

FDA testing occurs in healthy volunteers but not the vulnerable transplant patient. This type of problem also exists in pediatric populations. Some of the controversy centers in the ethics.

The FDA stated there was insufficient evidence to mandate such testing prior to bringing the generics to market. As of late last year the FDA had not ruled if tacrolimus will be characterized as a narrow therapeutic index range drug product.

One more point on the “narrow therapeutic index” ruling is that this ruling may dictate the substitution in states which have regulations regarding substitution of this category drug. States may have regulations but may rely on the FDA for this determination rather than determining this themselves, such as North Carolina has done for tacrolimus.

Binders

The next question relates closely to the above discussion. Would binders used in generics have an impact on a patient? How would one tell if there is a difference between the brand name and the generic?

Keep in mind that these two are standardized by FDA testing. First of all symptoms and blood levels need to be closely monitored in PSC and transplant patients. Liver enzymes help determine disease progression, recurrence, and/or rejection.

Blood levels are only necessary for tacrolimus. There are no blood levels tested for ursodiol nor have there ever been for routine monitoring.

Looking at references listing all inactive ingredients of these two drugs, there is quite a list. These may be binders, coloring agents (how a capsule or tablet has different colors), coatings for tablets, gelatin (if it is a capsule). Although these ingredients are listed for products, the formulation is the company secret.

The reason is that a company must spend the money to create a formulation to achieve first of all USP. They want to achieve a good Orange Book rating, which may take time and money, in addition.

In summary, I recommend if you are taking one of these drugs, follow a few simple rules.

- ◆ Talk to your doctor about the product you are currently taking.
- ◆ Most physicians are comfortable with generic ursodiol. Some patients may prefer a capsule versus a tablet for swallowing comfort. This is entirely acceptable and you must state this when providing your pharmacy with the prescription.
- ◆ Some physicians may have a preference on the tacrolimus. If your blood levels are difficult to maintain in range, you should discuss this with your doctor to help determine if it's due to a product change or something else causing erratic absorption or timing of doses and/or labs.
- ◆ If you and doctor have determined you require brand name, make sure your prescription states the proper notation for your state such as “Brand Medically Necessary” or “Do NOT Substitute.” You need to ask a local pharmacy what the state regulations are for this in your area and make sure your doctor writes this on your prescription.
- ◆ Lastly watch for changes in your symptoms as this can be a clue that you need your physician to evaluate your issues and make adjustments in treatment, perform further testing, or adjust doses in current drug therapy.

Transplant Center

Generic vs. Brand Name Drugs: Some Questions You Should Ask

Inspire, the magazine from Transplant Experience (www.TransplantExperience), which is issued by the pharmaceutical firm, Astellas Pharma, offered some advice for becoming your own advocate, particularly with regard to meds.

Yes, the company has an interest in keeping patients on brand name drugs, but the advice offered is useful. Astellas offers a PDF brochure, PROACTIVE, at its website, above.

Pharmacists are not required to tell you or your doctor if they decide to substitute a generic for a brand name drug. Some mail order pharmacies are required to make substitutions with generic meds.

Questions to ask your doctor about medications:

What is the name and purpose of each med?

Are generic versions available for any of my meds?

Which meds would you recommend I take as a generic? Which ones as brand name versions?

Are there situations when my pharmacist could change my med to generic?

What if my insurance company won't cover a brand name med that I need?

Questions to ask the pharmacist:

What's the difference in co-pay for a specific brand name vs. generic med?

Am I receiving the meds my doctor prescribed?

Is a co-pay card available to help with the cost of my meds?

The National Donor Sabbath Reminder: November 12-14

Check out this website for ideas on how to work with your faith community:

www.organdonor.gov/get_involved/donorsabbath.htm

Can you guess how often someone in this country needs blood?

Every two seconds.

Make regular blood donations if you can.
Encourage others if you aren't able to.
Organize a blood drive. You can save a life.

Fact-O-Rama

Generic Meds

Ursodiol: Actigall, the brand name version from Axcan, had sold \$76M worth of the drug in the year ended, March, 2009, according to company reports.

The generic version of Urso became available in 2009.

Tacrolimus: Prograf, the brand name version of a widely used immunosuppressant from Astellas Pharma, is now available as a generic from Sandoz.

The brand name drug reportedly generated \$929M in 2009 for Astellas, say industry experts.

Note: As always, PSC Partners recommends discussing any prescribed medication changes with your physician. See the Transplant Center article, page 25 in this issue, on generic meds and what to discuss with the medical team. See also the Ask a Pharmacist article on generics on page 22.

Help Other PSCers by Spreading the Word About Two Important PSC Partners Resources!

We know you think PSC Partners is a valuable resource. We've also made it easy for you and your doctor to help others get to know the resources available to patients, caregivers, and family members, especially if newly-diagnosed and wanting to know about our disease. On our website there are two brochures you can print out and take to support group meetings and to your specialist's office as informational handouts.

The **2010 patient conference flyer** is on the site at this address: http://www.pscpartners.org/sites/default/files/files/pdfs/Flyer_2010_2-11-10.pdf.

A **website announcement flyer** is at this URL: <http://www.pscpartners.org/brochures>.

While you're at the website's brochures page, you may want to check out and order or download our three brochures and pass them out as well. The more PSCers know about this disease, the better!

Get Moving

Spring: A Great Time for a New Beginning!

by Julianne Vasichek, who is Assistant Strength and Conditioning Coach for Women's Ice Hockey/ Women's Soccer, at the University of Minnesota, Duluth, and who will present on this topic at the May conference.

Spring is upon us! The days are getting longer, the light is coming earlier, and most importantly in Minnesota, the temperature is getting warmer! At this time of promise where the winter transition brings new life, I would like to bring forward some tips to continue the progression of including exercise in your daily life.

Guidelines

The American College of Sports Medicine (ACSM) provides a set of guidelines for weekly exercise. These can be found at www.acsm.org and click on Resources for General Public. As PSCers we should check with our doctors to approve the safety and intensity of exercise, including with certain medications, especially if you have multiple diagnoses or you are in the critical transplant stages. The ACSM guidelines represent an achievable goal, but one to take steps towards. I have provided some beginning steps in the table at the right for us to get started.

Proper Equipment

With this disease, we are constantly checking in with our bodies. Exercise is no different: we want to monitor when we work out, how we work out, and how we feel after working out. A workout log is a great way to track your progress. If you are having success with workouts or struggling, you can look back at your workout log to see if there is anything that can be changed. See list at lower left for what to track in the log

Clothing and shoes are next on the list. Examine them to see if they have ripped mesh, worn tread on the bottom, or compression lines in the weight bearing areas, such as under the heels. You should evaluate your shoes at least every six months. Also, make sure you pick out clothes that are comfortable for you. For example, I have issues with anything too tight right below my sternum, with the pressure causing discomfort. Your clothes should not distract you from the workout.

Workout Log/Journal Contents

Date, Medications Taken, Resting Heart Rate, Average Heart Rate of Session, Intensity of Session, Length of Exercise, Type of Exercise, How you felt before the session and after.

PSC Exercise Suggestions (Based off of ACSM format)
Levels based on previous activity levels

Beginner	Progression 1	Progression 2
Prev. less 3x/wk activity	Prev. 3x/wk activity	Prev. 5x/wk activity
10 min/day of cardiovascular @ moderate pace <i>or</i> 15 min. 3x/wk at vigorous pace <i>and</i> 2-4 exercises of 10-15 reps of strength exercise, 2x/wk. (i.e. hill or stair stepping, yoga, wall pushups)	20 min, 3x/wk cardiovascular @ moderate pace <i>and</i> 15 min 2x/wk at vigorous pace <i>and</i> 6-8 exercises of 10-15 reps of strength exercise, 2x/wk. (add some weights to exercises)	30 min, 3x/wk cardiovascular @ moderate pace <i>and</i> 20 min, 2x/wk at vigorous pace <i>and</i> 6-8 exercises of 10-15 reps of weight bearing strength exercise, 2x per week. (at least 3 weight exercises)

Monitoring Heart Rate

A heart rate monitor is one of the most important pieces of exercise equipment for someone with a chronic illness. As PSCers with different conditions and medications, as well as daily changes in how we feel, it is important that we additionally track our heart rate.

Of the many heart rate monitors, I have worked with those from two reputable companies, Suunto and Polar USA. The basic necessary functions are heart rate and chrono, or time keeping, functions. The monitor will come with a belt to fasten around your chest, and a watch to read the signal. Suunto seems to have the best belt for ease of conductivity, meaning that you can easily get a signal without the belt being tight. The belt should have a unique signal to the watch to prevent electronic interference.

Knowing your maximum and resting heart rates referred to in the table will help get you started in equating your heart rate with feelings of exertion. Once determined, these numbers help set exercise at specific intensities for different gains. As an athlete, I used my resting heart rate as an indicator of overtraining. A 5-10 bpm difference was a red flag, to rest. Having PSC, I can use the information to determine exercise intensity on heavy fatigue or good days. I feel, similar to you, the more I know about my body, the bigger my tool box to take on the fight!

If you have questions on this article, please contact me at jvasiche@d.umn.edu.

Determining Resting and Maximum Heart Rate (HR)		
Resting Heart Rate Methods to find:	Resting heart rate indicates the amount of times your heart needs to contract at rest. Affected by illness, stress, rest, fatigue, overtraining. Should decrease with fitness improvement.	
	Each morning, before getting up, find radial or carotid pulse and count the beats for 1 minute. Record in your workout journal. Take average every two weeks.	
Maximum Heart Rate Methods to find: Submaximal Tests These do not require that you exercise to complete exhaustion, but also are more of an estimate.	Maximum heart rate indicates the maximum amount of times your heart can contract in one minute. Will not change with exercise, and is very individual.	
	1-Mile Walk Test 400 m or 440 yd track (4 laps = 1 mile) Walk 4 laps at a quick pace. Take your heart rate avg. for the last lap. Prev. no exercise: Add 40 beats per min (bpm) Prev. 3-5x wk exercise: Add 50 bpm Prev. 5-7x wk exercise: Add 60 bpm	Step test Use an 8 inch step Begin stepping up in a four count rhythm (right-up, left-up, right-down, left-down) @ 20 sets per minute, for 3 min. Take avg. heart rate of last min. Prev. no exercise: Add 55 bpm Prev. 3-5x wk exercise: Add 65 bpm Prev 5-7x wk exercise: Add 75 bpm
Methods to find: Maximum Tests These tests will put you very close to your maximum heart rate. Manual HR: Find radial or carotid pulse, count beats for 10 sec and multiply by 6	Run Test <ul style="list-style-type: none"> • Use a track at least 200m or 220 yds long (in or outdoor) • Jog 800 m at a moderate pace (2 laps on big track) • Speed up pace for 200m • Sprint for 200m • Take heart rate right away 	Pool Test (Running in water) <ul style="list-style-type: none"> • Do not touch bottom • Jog in the pool (just like running) at a moderate pace for 4 sets of 30 sec w/ rest for 30 secs • Sprint for 10 secs • Rest 10 sec, sprint for 20 secs • Take heart rate.

Fundraising

Willing to Sweat for PSC Partners

*by Steve Howard, who is
training in Canton, Michigan.*

When I was first diagnosed with this disease in 2000, I was told by my doctor that she could only guarantee one year before I would need a liver transplant. That is quite a blow to a 31 year-old husband and father of three and seven year-old girls.

I worried most of all that my kids wouldn't be old enough to remember me. It has now been 10 years and although there have been a few bumps along the way, I am fairly healthy compared to some of the other people affected with this disease. Just lucky I guess!

I have never organized a fundraiser before but I believe in all the work that PSC Partners is doing. I can't say enough good things about this organization. The website is amazing and is packed full of

valuable information. I attended the conference in Chicago in 2009, and it was an emotional experience for me.

Surrounded by other people and their families who are in the same situation, was mind numbing. The agenda was packed with doctors and experts all representing different but related fields tied to PSC. It was exciting to hear about all the promising research being done. I get emotional just writing this, but the feeling of being surrounded by my PSC "family" was extremely comforting. I felt depressed and alone when I left Chicago that weekend. I felt somehow protected when I was around the PSCers! Sort of like feeling safe if you went to a police conference and were surrounded by officers.

2009 Triathlon

I started doing sprint triathlons in 2005 as a way to maintain overall good health for disease management. The effort has grown into somewhat of a passion for me (passion is a funny word for me cuz I'm basically a lazy person). It is my own personal way of wrestling control of PSC away from the disease to something I can control.

I competed in my first 1/2 Ironman event last year in June in Monroe, MI. It consisted of a 1.2 mile swim (in Lake Erie), a 56 mile bike ride, and a 13.1 mile run.

I trained hard for the race but in April I had a setback. I started to feel extremely fatigued while training and my body started to cramp up regularly. That had never happened to me before and I attributed it to just hard exercise. However, when I started to itch all over (and I mean ALL OVER) I knew something was going on with my liver.

I went to see my liver doc at the University of Michigan and the blood work confirmed that my enzyme levels had risen sharply. I would need to undergo yet another ERCP. It was a hard hit mentally because I had gotten it into my head that I was going to beat this thing through exercise.

It was sobering to know that I wasn't in control at all. I decided that I would do the ERCP, but not until I finished the triathlon first! I had trained too hard to quit at that point.

On race day I felt good. There were a series of morning thunderstorms which made the waves in Lake Erie pretty

daunting. (Translation: I was really, really scared).

Unfortunately, only about 3/4 of a mile into the swim, my legs completely cramped up. It was the worst pain I had ever felt and I couldn't swim.

Another swimmer (I don't know who you were but you may have saved my life) helped get me to a kayak where I stretched and stabilized myself.

I considered quitting but I decided to keep swimming and got to shore in one piece, albeit later than I had planned. The rest of the race consisted of constant quad cramping and pain, but at least I finished! Three weeks later I had my ERCP and my primary bile duct was ballooned.

The 2010 Fundraising Goal

I'm a glutton for punishment. After swearing off triathlons last year, I'm going to try this 1/2 Ironman thing one more time on July 10th, 2010, in Muncie, Indiana. (1.2 mile swim/56 mile bike/13.1 mile run.)

I'm competing for all the people with PSC that I met last year; for teenagers who have this disease and feel sad because they don't want to date anyone because they think they'll die anyway; or for those that have suffered for decades and continue to be positive role models in perseverance. Or, I'm not naive, there will come a day when I probably will be too sick to do triathlons.

But while I'm able, I'm willing to sweat for PSC Partners.

In life you realize that there are always people worse off than you. I've been lucky so far. In some ways my life is better because of PSC. It helps put small things in perspective. In today's economy, everyone is watching their dollars. There are literally thousands of good causes that would benefit from donations.

Hopefully you can see your way to donating any amount you see fit to this cause. I don't have a real dollar target goal, but I put \$1000 on the board because I had to put something! It's all good.

Here's my website and my story, with photos, and information on how you could contribute:

<http://www.firstgiving.com/pscsteve>.

Donation Update

DECEMBER 11, 2009 to February 28, 2010

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PSC Partners Seeking a Cure received a generous donation from Dike & Rilee Ajiri in honor of the following:

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PSC Partners Seeking a Cure Treasurer's Report December 31, 2009

Following is an update of the current financial position through December 31, 2009 of PSC Partners Seeking a Cure Foundation.

Year to Date 2009

Fundraising income is detailed below. In order to ensure that restricted funds are properly accounted for, a separate account was set up. Unfortunately, this means that they are not designated to a particular fundraiser. During 2009, \$10,000 of the restricted funds were a straight donation and \$44,562 were designated to the Road to Chicago. Total for Road to Chicago was \$145,164. Total income for the 2009 conference is \$26,480 + sponsor income of \$20,098.

Total income for 2009 was almost \$100,000 greater than 2008, thanks to a \$50K increase in donations and close to a \$40K increase in fundraising income.

Expenses were \$160,747 greater in 2009 than 2008. 2009 conference expense was \$44K higher. We were able to donate a total of \$136,000 in research grants, an increase of \$110,000 over 2008!!!

The balance sheet includes \$7500 in prepaid expense – these were expenses for the 2010 conference.

Total assets increased \$91K to a total of \$509K.

As always, please direct any questions/comments to Deborah Wente, Treasurer at debs_3@charter.net.

Fundraising Income Detail

	<u>Dec 09 YTD</u>
Cash Dividend	4686.79
CD	0.00
Conference	26480.50
Donations	59041.84
Grocery Cards	1518.31
Holiday Cards	2320.00
Miscellaneous Fundraising	6468.71
Money Fund Dividend	10.55
Notecards	263.80
Other Sponsors	0.00
Pay Pal Fee	-362.14
Recycling	11.10
Restricted Funds	54562.40
Road to Chicago	77124.75
Road to Connecticut	15750.00
Save the Day	16865.57
Sponsors	20098.10
Wristband	<u>0.00</u>
TOTAL	<u>284840.28</u>

	<u>Dec 08 YTD</u>	<u>Dec 09 YTD</u>	<u>Difference</u>
Income			
300 · Donation Income	20410.23	59041.84	38631.61
301 · Conference Income	20618.95	26390.14	5771.19
302 · Sponsor Income	21160.00	20098.10	-1061.90
303 · Fundraising Projects	125270.41	120353.55	-4916.86
304 · In-Kind Contributions	5171.51	8113.93	2942.42
305 · Interest Income	20.34	3476.03	3455.69
306 · Cash dividends	6665.96	4697.34	-1968.62
307 · Capital Gains	57.91		-57.91
310 · Restricted Donations		<u>54562.40</u>	<u>54562.40</u>
Total Income	<u>199375.31</u>	<u>296733.33</u>	<u>97358.02</u>
Expense			
500 · Admin Fee	1660.39	1848.52	188.13
502 · Conference Expenses	14877.80	58832.92	43955.12
503 · Pay Pal Expenses	194.48	362.14	167.66
509 · Insurance	295.00	1150.00	855.00
508 · Licenses and Taxes	1150.00	295.00	-855.00
510 · Labor	0.00	1905.00	1905.00
521 · Expendables	188.95	5298.93	5109.98
525 · Fundraising Project Expenses	2307.49	3694.10	1386.61
530 · Advertising	5165.00	200.00	-4965.00
550 · Honorariums	0.00	3000.00	3000.00
556 · Research Grants	26000.00	136000.00	110000.00
66900 · Reconciliation Discrepancies	<u>0.00</u>	<u>0.33</u>	<u>0.33</u>
Total Expense	<u>51839.11</u>	<u>212586.94</u>	<u>160747.83</u>
Net Income	<u>147536.20</u>	<u>84146.39</u>	<u>-63389.81</u>

	<u>Dec 31, 08</u>	<u>Dec 31, 09</u>	<u>Difference</u>
ASSETS			
Current Assets			
Checking/Savings			
101 · Checking Account	48812.37	28939.21	-19873.16
103 · Pay Pal	-17.67	-17.67	0.00
104 · Charles Schwab	<u>369156.25</u>	<u>472585.21</u>	<u>103428.96</u>
Total Checking/Savings	<u>417950.95</u>	<u>501506.75</u>	<u>83555.80</u>
Other Current Assets			
405 · Prepaid Expense	<u>0.00</u>	<u>7500.00</u>	<u>7500.00</u>
Total Other Current Assets	<u>0.00</u>	<u>7500.00</u>	<u>7500.00</u>
Total Current Assets	<u>417950.95</u>	<u>509006.75</u>	<u>91055.80</u>
Other Assets			

410 · Available restricted funds		24562.40	
415 · Restricted funds payable		<u>-24562.40</u>	
Total Other Assets			<u>0.00</u>
TOTAL ASSETS	<u>417950.95</u>	<u>509006.75</u>	<u>91055.80</u>
LIABILITIES & EQUITY			
Equity			
299 · Retained Earnings	285258.63	432794.83	147536.20
3000 · Opening Bal Equity	-0.10	-0.10	0.00
401 · Investment Adjust to FMV	-10360.18	-2657.89	7702.29
402 · Income Reinvested this Period	-4483.60	-5276.48	-792.88
Net Income	<u>147536.20</u>	<u>84146.39</u>	<u>-63389.81</u>
Total Equity	<u>417950.95</u>	<u>509006.75</u>	<u>91055.80</u>
TOTAL LIABILITIES & EQUITY	<u>417950.95</u>	<u>509006.75</u>	<u>91055.80</u>



PSC PARTNERS SEEKING A CURE

PSC Partners Seeking a Cure is a 501(c)3 nonprofit foundation that endeavors to find a cure for Primary Sclerosing Cholangitis.

The three-fold purpose of the PSC Partners Seeking a Cure foundation is to: raise funds for research on the causes and cures of PSC, provide education and support to PSC patients and their

families, and promote awareness of PSC and organ donation.

Ricky Safer is the principal contact person for the PSC Partners Seeking a Cure Foundation. Reach her at: contactus@pscpartners.org

Tax-deductible donations can be sent to: PSC Partners Seeking a Cure, 5237 South Kenton Way, Englewood, CO 80111 with a check made out to: PSC Partners Seeking a Cure.

Website

www.pscpartners.org

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The Duct Newsletter

Editor: Pat Bandy
(newsletter@pscpartners.org)

Contributors to this issue: Pat Bandy, Rachel G., Steve Howard, Tom Hill, Pauline S., Sandi Pearlman, David Rhodes, Ricky Safer, Julianne Vasichek, and Deb Wentz

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