PSC Partners Seeking a Cure

Newsletter

Vol. 1, Issue 5, May 2005

Edited by David Rhodes and Ricky Safer

www.pscpartners.org

In This Issue:

This issue of the newsletter is a continuation of our report on the First Annual PSC Partners Seeking a Cure Conference, held in Denver, CO, April 29 - May 1, 2005.

CONFERENCE FOR PATIENTS AND CAREGIVERS

It includes brief synopses of several of the talks that occurred on April 30, 2005, a description of the questions posed at the conference, and answers given by speakers, and a few photographs from the conference.

As noted in the previous issue of the newsletter, the Conference was attended by 82 people from 21 different states, the United Kingdom and Canada. It was an incredibly informative meeting, and we are deeply indebted to all of the speakers for their contributions. We are especially thankful to the team of doctors from the University of Colorado Health Sciences Center.

ROCKY MOUNTAIN HIGH

The week before our inaugural conference, as I sat in my paper-strewn office trying to finish the last minute details for the weekend ahead, I realized that I felt confident about our choices of venue, food, weekend schedule, and certainly our incredible slate of speakers. My one lingering doubt concerned something we had no control over: the tone of the conference. I had never before met another PSCer. What would it be like to actually get to meet my online buddies in person? Will it be depressing for all of us to get together?

Now, one week later, I can't believe that I wasted one moment ruminating about this. On Friday evening, my first bear hug from Bill immediately erased all my doubts. I now realize that it's the attendees that made the conference. I could not have hand picked a more special group.

I have always tried to avoid stereotyping groups of people, but I feel compelled to share my personal impressions of PSCers.

- PSCers have positive energy that is unstoppable. Put a group of PSCers together in a room, and the buzz is evident and overwhelming
- PSCers are an extremely intelligent bunch. We thirst for more knowledge about our disease, and we use it wisely. The cliché "Knowledge is power" certainly holds true here.
- PSCers are compassionate souls. Even those who are on the transplant list always seem to have time to encourage others in need.
- PSCers have an uncanny ability to find humor in everyday health issues.
- PSCers represent an endless variety of talents and interests, and they are eager to share their expertise. We are a formidable group, passionate about defeating and conquering PSC.
- PSCers are tenacious. When PSC knocks us down, we pop back up with renewed energy, knowledge, and determination.
- The younger generation of PSCers shares their youthful perspective on beating this disease and their philosophy of living life to the fullest with the older PSCers like myself, which helps our perspective greatly.
- We PSCers may be a diverse lot, but everyone is welcomed unconditionally into the group.
- PSCers are accompanied by sparkling caregivers, who are a special group as well. We PSCers hope that our caregivers know how much we appreciate them!! Their support keeps our spirits up.

I gained so much medical knowledge from our brilliant speakers, but it was you, the attendees, who made an indelible impression on me. I feel like I have gained a new family, and I miss you all enormously. One week post-conference, I still wake up feeling the warm glow of our group. I am so inspired by all of you! With all of us working together (this year's attendees and all the online members who were there with us in spirit), I know that we will get our Cinderella disease into the medical spotlight, and provide funding for much needed research. Thank you all for changing my life in such a positive way!!!!!

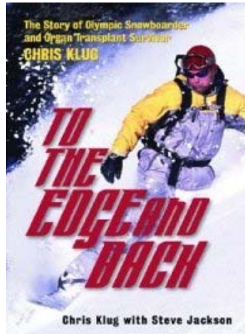
Ricky Safer

The audience, without whom, there would not have been a conference. Thank you all for your participation!

Chris Klug

April 30, 2005 (contd.)

We were delighted to have Chris Klug, snowboader, Olympic medal winner, author, and PSC liver transplant recipient, join us at the conference. Chris gave a very inspiring talk entitled ... "To the Edge and Back"... the same title as his recent book. Chris first showed a movie of highlights from his snowboarding career and Olympic competitions. He described how his career as a snowboarder was interrupted by his PSC diagnosis in the early 1990's. Liver disease was first detected by elevated liver function tests. This was followed by a 1 year "fishing expedition" to identify the cause, culminating in a liver biopsy, ERCP and an official PSC diagnosis. Chris was placed on the liver tranplant list in 1998, but even during this time although he had a few ERCPs and infections, he stayed on the snowboarding competition circuit. In the spring of 2000, after winning the national championship, he developed flu-like symptoms, and felt worn-down with lingering pain in the liver. He realized his liver was shutting down, and he was "hitting the wall". He eventually got "the call" in July 2000, and underwent a liver transplantation at the University of Colorado. He remarked how positive he was going into surgery, but confessed to being a little scared (and who would blame him!). He was told that when he woke up from surgery, he shouted ... "I rule" .. and within days he felt like a new engine had been installed under the hood. Within 4 days, Chris was riding a stationary bike, and within 7 weeks was on the snowboard again, and proceeded to have his best season ever. In 2002, Chris had the high honor of carrying the Word Trade Center flag into the Olympic stadium during the opening ceremony. He was awed by the sound of 55,000 silent people showing their respect for the flag. At these games, Chris achieved a life-time ambition, and won the bronze medal. Chris emphasized to the audience that transplants do work ... he feels stronger and healthier than ever. Although he has to continue to take transplant rejection medication, and has to wear more sunscreen, and have a colonoscopy every 2-3 years, he has made very few changes to his life-style. He is extremely thankful to his liver donor. The donor's family attended the 2002 Olympic Games, and it meant a great deal to them to share in the victory. Chris is equally thankful to his transplant team, and to his parents. He is now a tireless spokesperson for organ donor awareness, and works closely with pediatric transplant recipients. He has become an inspiring 'poster-boy' of liver transplantation, and we hope that Chris can continue to work with PSC Partners Seeking a Cure to promote research, education and support for families affected by PSC. We are deeply indebted to Chris for attending the conference, and for sharing his remarkable story with us. We wish him great success in the 2006 Olymic Games in Italy. We were delighted that Warren and Kathleen Klug (Chris's parents) could join us at the conference!



April 30, 2005 (contd.)

Following lunch on April 30, Dr. Lisa Corbin (Medical Director, The Center for Integrative Medicine, University of Colorado Hospital, Denver, CO) gave a talk on "CAM Therapies"; where "CAM" stands for "Complementary/Alternative Medicine". Her talk was generally divided into six areas:

- Terminology
- Risks, benefits, and balance of CAM
- Specific CAM therapies
- Finding a good practitioner
- Summary
- The Center for Integrative Medicine

Dr. Corbin explained that CAM represents therapies not usually associated with hospitals or medical schools, and include acupuncture, massage therapy, and chiropractic therapies. She noted that certain of these therapies are not without risk because they may either directly or indirectly harm your health (e.g. by reducing efficacy of conventional treatment, and replacing curative conventional care). However, they also have potential benefits such as symptom control, and wellness promotion, and tend to have lower cost and risk than conventional therapies. Dr. Corbin emphasized the need to be informed about specific risks and benefits, and stressed the importance of consultation with your health care provider to obtain this balanced view, and to avoid misconceptions and potentially harmful interactions. Dr. Corbin discussed some examples of harmful CAM therapies, including colon enemas, chelation therapy, IV therapy, restrictive diets, megavitamins and some herbs and supplements which can cause direct or indirect injury/toxicity. CAM therapies specifically discussed by Dr. Corbin included mind/body techniques, exercise/diet, herbs and supplements, acupuncture and massage. Dr. Corbin emphasized the importance of getting plenty of sleep, getting enough exercise, and eating a well balanced diet. With regard to herbs and supplements, Dr. Corbin noted that unlike standard prescriptions, herb and supplement marketers are not required to prove safety or effectiveness, they are not required to enforce quality control, and the products can vary tremendously in concentration of ingredients. "Natural" does not necessarily mean "safe" ... some herbs can be toxic to the liver, can thin the blood, and may cause drug interactions. In general, one should look for a well-labeled brand (containing lot #, expiration, dosing, ingredients), avoid combination products, and inform your health care providers. Some "hot supplements" discussed by Dr. Corbin included: probiotics, omega-3 fatty acids (fish oils containing EPA and DHA), and milk thistle. The reader is encouraged to read through the very thorough slide presentation and additional reading material list kindly provided by Dr. Corbin. These materials are included on the conference CD (see p. 10 of this newsletter for details of how to order the CD).

The Center for Integrative Medicine

University of Colorado Hospital

April 30, 2005 (contd.)

Georgeane Vigue RD, CNSD (Clinical Dietitian at University of Colorado Hospital, Denver, CO) gave a talk on “Nutritional Issues with PSC”. She first described that chronic cholestasis can result in a number of nutritional problems including fat malabsorption (steatorrhea). This tends to be associated with fat-soluble vitamin deficiencies (especially deficiencies in vitamins A, D, E, and K), impaired calcium absorption (potentially leading to metabolic bone disease), and over-accumulation of cholesterol (hypercholesterolemia). Treatments recommended by Georgeane included:

- A low fat diet
- Fat-soluble vitamin supplementation (oral, IV)
- Calcium supplementation

For severe weight loss, Georgeane advised:

– Small, frequent meals and snacks
– Oral supplements with medium-chain tryglyceride oil
– Nutrition support (tube feed vs. parenteral nutrition)

Georgeane noted that advanced liver cirrhosis can result in special nutritional problems for the PSC patient, particularly in relation to ascites and hepatic encephalopathy. She recommended sodium and fluid restriction for ascites, and protein restriction for encephalopathy:

- Ascites:

  – Sodium restriction (2 g/d)
  – Fluid restriction

- Encephalopathy:

  – Protein restriction

Georgeane also commented that inflammatory bowel disease (IBD) (mostly ulcerative colitis, and sometimes Crohn’s disease) is frequently associated with PSC, and that IBD can in turn come with special nutritional deficiencies, sometimes requiring supplements:

- Ulcerative colitis:

  – Iron deficiency

- Crohn’s disease:

  – Folate, zinc, iron, and B12 deficiencies

Georgeane concluded by noting that, in general, individuals with PSC need to consume adequate calories and protein to maintain a healthy weight, and good nutritional status.

April 30, 2005 (contd.)

Marlene Murphy

Marlene Murphy, Executive Director of the Donor Awareness Council, Denver, CO, gave a talk on “Organ Donor Awareness: Organ, Eye and Tissue Donation 101”. Marlene first described the challenging problem that nationwide, over 88,000 men, women and children are currently awaiting life saving organ transplants, but only 27,000 actually received transplants in 2004. In dealing with this issue, an additional problem is that 90% of people support organ and tissue donation, but only 34% know the proper steps for committing to donation. Some common reasons why people say “no” to donation, include:

- Age: “I am too old.”
- Self-rule out: “I have had cancer.”
- Trust: “They will take me before I am dead.”
- Religion/Culture: “My religion won’t permit donation.”

The actual criteria for organ donation are:

- No Age Limit
- Declaration of Brain Death
- Mechanical Ventilation
- No Active Cancer
- Negative HIV

The chief goal of the Coalition on Donation is to overcome some of the misconceptions about organ donation through education. Its stated mission is “***To inspire all people to Donate Life through organ, eye, and tissue donation”.*** Towards this goal, it has undertaken an extensive media campaign to reach many different audiences, including African-American and Hispanic audiences. The Coalition on Donation has adopted a logo to provide a sustained unified national message about donation, and to provide a strong, positive visual image for educational and promotional materials. Marlene encouraged each of us to become aware of the Coalition on Donation web site:

http://www.donatelife.net/

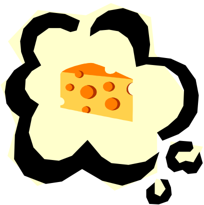
and to find out how to become an organ and tissue donor in our own state. She encouraged us to volunteer, and educate and inform others within our own communities.

If you would like to contribute an article to a future issue of this Newsletter, please e-mail it to David Rhodes:

rhodesdavid@insightbb.com

Some questions and answers at the 2005 Conference in Denver, CO; April 30, 2005

Question	Answer
Is there a correlation between biliary cancer and the extent of PSC?	Some PSC patients develop cholangiocarcinoma immediately; others only after a long time; the reason for this difference is not known.
What is the course of IBD after liver transplantation?	After liver transplantation, one would expect IBD to disappear. But this is not the case; it can get worse. Dr. Trotter recommends colectomy at the time of liver transplantation.
Would you expect that removing part of the diseased liver would help the PSC patient because the liver can regenerate?	Unfortunately, the regenerated liver would also be diseased, and no benefit would be expected.
What is the prognostic significance of p-ANCA?	None; they are not helpful to follow.
What is the latest on stem cell research for PSC?	There is very little on the radar screen for PSC. There is some work being done on IBD, and progress is being made on stem cells from bone marrow that can be differentiated into liver cells (hepatocytes), but clinical applications are still lacking.
Are there any predictors of "hitting the wall"?	Dr. Trotter likens this to driving a '94 Honda; you don't know exactly when it will conk out. You try to look after it and drive it as long as possible. One predictor might be bilirubin level.
What is the recurrence rate of PSC after transplantation?	It is estimated that 30% of PSC liver transplant recipients may get recurrent disease. Because ursodiol is being prescribed for recurrent PSC, this may prove to be a good way to assess the effectiveness of this medication, if given early.
What is the incidence of bile-duct cancer after liver transplantation?	There has been only 1 case report, from Duke University.
Is there a correlation between high cholesterol and PSC?	PSC does affect lipid metabolism, and can lead to cholesterol rich deposits (Xanthomata) — this reflects the inability of the liver to get rid of cholesterol and its degradation products.
Does PSC run in families?	There is an increased risk of PSC in children of PSC patients, but this disease is genetically complex, and is likely not determined by a single gene.
Twins have been known to both have PSC, but they may develop this disease at different rates ... why?	We need more studies on this ... there must be environmental influences, or other factors involved.
In siblings who are not twins, is there an increased risk of PSC or IBD?	For PSC there is little data; for IBD there is evidence for an approximately 15% risk of getting the disease from an affected father or mother.
Is it possible that the IBD associated with PSC is neither UC nor Crohn's, but a third, as yet unnamed disease?	It behaves a lot like UC, but it is possible that it may be a separate entity.
Could you comment on split liver donations for pediatric patients who can't take full livers?	This procedure is not routine; there are serious logistical issues when the split is not being done by the same team.
What are the benefits of withdrawing from prednisone?	Prednisone can cause diabetes, osteoporosis, and as many as 30 other side-effects. Some newer immunosuppressants include Rapamycin and Celcept.
Is there any data collected on the health of the donor's liver in living donor liver transplants?	Yes. 70% of a healthy liver can be removed, and yet still provide a healthy life. The liver has a remarkable ability to regenerate; it can be regenerated fully in 6 weeks in a healthy donor. The Colorado team is planning an NIH living donor prospective study to address this issue.
What is the incidence of post-transplant complications?	Approximately 70% will experience abnormal kidney function, 50% will experience hypertension, and 20% diabetes. How to treat rejection is no longer a big issue; we need to learn how to improve patient quality of life by minimizing medication levels. This requires detailed patient follow-up.
What can be done to stay fit?	Work out hard, but keep it fun; hydrate well, and eat right.
Is hepatic encephalopathy completely reversible after transplantation?	Yes, it is completely reversible.



Bill Wise

One of our foundation goals is to increase organ donor awareness. We encourage U.S.A. 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….“While 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.”

Give Life

Additional Contact Information

Ricky Safer is the principal contact person for our PSC Partners Seeking a Cure Foundation. She can be reached at:

Ricky Safer
PSC Partners Seeking a Cure
5237 S. Kenton Way
Englewood, CO 80111

e.mail: **pscpartners@yahoo.com**

Confessions of a Low Fat Cheesehead

I was thinking the other night about a topic for my inaugural column when I came over all peckish. Now, “peckish” for me used to mean “fire up the grill, throw on a ribeye, break out a few beers, sauté some onions and mushrooms, deep fry some potato wedges, and smother it all in cheese.” That’s actually what we do here in Wisconsin… deep fry things, smother them in cheese, and wash them down with beer. It’s ritual. There’s actually a statue honoring the man who invented the fried cheese curd. After all, he figured out how to get cheese, beer (in the batter), and deep frying all into one food. Unfortunately, “peckish” now usually means a rice cake and a glass of skim milk or maybe a dill pickle with a diet soda.

How did I come to this? Where did all the butter, cheese, steaks, and wine go? Why does even the thought of a king cut medium-rare prime rib and jalapeno poppers make my flesh crawl? What did I do to deserve this life of bland-dom? Gut… why hast thou forsaken me?!?! (Sorry… I get emotional about food sometimes.)

We all know the answer to that question (if you don’t… remember, you’re reading a PSC newsletter), but not everyone in my inner circle does. It’s actually kind of a badge of honor among my buddies (all of whom are over six feet tall and have long since passed 200 lbs… go figure) to see who can be the biggest pig. It’s a bit dicey for me to play along, but that hasn’t kept me from trying. Some of the guys are on to me ‘cuz, frankly, they were there when a steak sandwich with grilled onions, cheese fries, and a couple beers landed me in the hospital last fall. Still, I thought I’d put together some helpful tips for those of you trying to keep your dietary restrictions on the down low… or is it low down… downtown… whatever…

1) Wear loose clothing. It’s harder for them to tell that you don’t have a beer gut anymore if you wear baggy sweatshirts and coaching shorts. It’s also helpful if the clothing has beer logos or something like “I’m With Stupid” on it.

2) Keep the label of your “beer” bottle carefully turned in toward the palm of your hand. Nobody can tell you’re drinking NA if they can’t see the label. Unless you’re dumb enough to let them taste it.

3) Go ahead and order the steak. Just make sure it’s a sirloin or maybe a filet. Way less fat than ribeyes and prime rib, so you won’t actually turn yellow before their eyes.

4) Two words… “baked potato.”

5) Tip waitresses at your regular haunts well. Soon they’ll just bring you the low fat sour cream and pseudo-butter without you having to whisper conspiratorially to them.

6) Do most of your eating in the privacy of your own home. Avoid the public humiliation that comes from having to order the Weight Watchers special with lo-cal French dressing and a Diet Coke when your cronies are having smoked salmon by simply saying, “I ate at home.”

7) Give your kids whatever they want. They blab. Better yet, send them away to private school.

8) When hosting a cookout, make sure the food packaging is destroyed before the guests arrive. I defy anyone to identify a bison burger with a slice of reduced fat cheese and some no fat Thousand Island in a lineup.

9) Tabasco sauce. You can eat damn near anything with enough Tabasco on it. Plus, your buddies will give you bonus points while missing the real issue. For instance, “Can you believe how much Tabasco he put on that tofu-veggie-kabob?!?!?!”

10) If you get busted in a compromising comestible moment, blame it on your wife. Every guy knows that if the wife suggests you shed a few pounds, you make at least a token effort at it.

There are certainly more, and maybe I’ll do a follow up column on it someday. But for now, this should be enough to protect your “rep” for a bit fellas. Ladies, do us a favor and just don’t “out” us in public. We’re already feeling a bit vulnerable. You all can feel free to send me your tips at **gmoobad@yahoo.com**

Bill Wise

Update on Donations to PSC Partners Seeking a Cure

(by Ricky Safer)

Here is a list of our recent individual donors (since March, 2005)

In honor of:	Donor:
Daniel Kantor	Daniel and Selma Mandel
	Ed and Marjorie Small
	Shirley Small
	Helen Rosen
	Josephine Lerro
	Shirley Newman
	Raymond and Barbara Breakstone
	Harold and Felice Golden
	Estelle Mannes
	Albert and Maureen Debiccari
	Pondfield Hairstylists, Inc.
	Harriet Shapiro
	Georgette and Thomas Hyman
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Billy Bria	G.K. and V.M. McMaster
	Louis and Lorette Nosal
	Margaret Annino
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	Edward and Juliette Larsen
	Rosemarie Bria
	Carla and Jack Shanks
Dave, Lee, and Ricky	Tim and Mary Wholey
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Jason Drasner	Lawrence and Linda Rich
Ricky Safer	Meredith Harris
	Lillian Wachtel
	Bob and Mimi Safer
	Mike and Cindy Goldman
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	Debbie and John Abrams
Marco Ginefra	James and Lisa Karkosky
	Charles and Susan Ray
Josh Miletic	Sandra Aiello
	Joyce Garris
Jecy Belmont	Reggie and Jeff Belmont
Anonymous	Jessica Paroly
Anonymous	Daniel and Marsha Adams
Denise Boyd	Shelley and Fred Hussey
All fellow PSCers and their care-givers	Ricky and Don Safer
For all the support we receive on this site	Alison Organ

In memory of:	Donor:
Brian Stewart	Jon Shapiro
Shauna Saunders	Ken and Helen Saunders
	Shelley and Fred Hussey
Helen Elizabeth Cavanagh	Donald and Jeannie Meier
	William and Dolores Gehrke
	Robert Leverenz
	Michael Froh and Susan White
	Steven and Helen Timm
	Robert and Anne Schroeder
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	Elaine Hitchcock
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	Anthony and Charline Bocchini
	Thomas and Elizabeth Schueller
	VJ and KM Baus Vidl
	Shirley Kade
	Deb and John Wente
Dr. Komitor's Dad	Don and Ricky Safer
Mette	Judy and Arne Myrabo

Here is our newest corporate donor:

University of Michigan MFit

Program – Gold Level Sponsor

Thank you to all our donors for helping us reach our ultimate goal of finding a cure for PSC!

Making Donations to PSC Partners Seeking a Cure

Tax-deductible donations can be sent to:

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

with a check made out to:

PSC Partners Seeking a Cure

Alternatively donations can be made on-line via PayPal (**https://www.paypal.com**) to **pscpartners@yahoo.com**

Please include a note to indicate who the donation is in honor and/or memory of, and your return address.

We offer several levels of sponsorship

- Platinum level: $10,000
- Gold level: $5,000
- Silver level: $2,500
- Bronze level: $1,000
- Copper level: $500

Thank you for your generosity!

“The Dual Diagnosis: PSC and Halitosis”

by Shelley Hussey, wife of Fred, PSC 03/04

To the tune of “The Beverly Hillbillies” theme song:

Gonna tell y’all a story ‘bout a man named Fred,
In ’95 his LFTs were el-e-va-ted,
The family doc said, “Fred, your tests—they seem to show . . .
You may have hepatitis, to the gastro you should go!”

. . . gastroenterologist, that is . . . digestive doc . . . drives a BMW . . .

Well the first thing ya know, they’re suckin’ blood from Fred,
Drained him so plum dry, that he shoulda’ been dead.
Doctor said, “Son, the hos-pital’s the place you oughta be,
So we can do an ultrasound and solve this mystery . . .”

. . . medical mystery that is . . . liver ultrasound . . . goop on stomach . . .

The ultrasound was done, doc said: “Fred, here’s what’s the matter:
Your liver’s aggravated from the stones in your gallbladder.
We’ll take that sucker out; LFTS—they should recede,
Just sign the dotted line and we’ll schedule surgery . . .”

. . . gallbladder surgery that is . . . NOT liver removal . . . or we’re talkin’ dead Fred . . .

Fred got second, third opinions but the doctors all concurred,
Gallbladder was the culprit, so Fred took them at their word.
Surgeons took the organ out and did a liver biopsy,
They found slight inflammation ’round the biliary trees . . .

. . . bile duct “trees” that is . . . thousands of ‘em . . . not to worry . . .

The years they come and go, Fred has routine LFTs . . .
Enzymes climbing ever higher—*what could be this strange disease?*
Fred decided, “No more blood tests! There’s nothing wrong with me!
This condition is benign—a liver “fluke,” can’t you see?”

. . . haha . . . liver “fluke” . . . very funny . . .

In the Fall, 2003, Fred showed pronounced fatigue.
His wife felt within her gut this liver prob’ was “major-league.”
She nagged Fred to the gastro, tests were “inconclusive, muddy,”
A new biopsy was ordered: “*The results we’ll closely study*.”

. . . “Study nothing!” Fred said . . . no biopsy . . . no way!”

But after doing liver research, he quit making such a flap,
And agreed to second biopsy (it was a pleasure nap).
Docs stared blankly at the slides: “What IS this—we don’t know!”
So they shipped Fred’s liver sliver to the mighty Mayo . . .

. . . Mayo Clinic that is . . . mighty fine liver docs . . . real fine . . .

The Mayo marvels nailed it, Fred’s report had this decree:
“Fibrosis, bile ducts blocked; this is Stage Two PSC.”
Fred and wife they dropped their jaws, at this dire diagnosis,
But soon they shut their mouths due to offensive halitosis . . .

. . . bad breath that is . . . real bad . . . shut yo’ mouth . . .

Fifteen months have come and gone since PSC’s been on their minds,
But the Husseys’ sense of humor helps them through the daily grind.
Fred’s wife Shelley finds support on the PSC group board,
While “Sigmund Fred” reads psychology—and paints the house, dear Lord!

. . . three story house . . . forty-foot ladder . . . pray hard . . . real hard.

The End

To Betaine or Not to Betaine? That is the Question

by David and Judith Rhodes

At the 2005 conference in Denver, David Rhodes mentioned that our son is being ‘encouraged’ to eat spinach, which is a rich source of a compound called betaine (also known as glycinebetaine, or *N,N,N*-trimethylglycine). This compound has been known for some time to maintain an important cycle in the liver, known as the methylation cycle. It stops homocysteine (a ‘bad thiol’), from building up, converting it to methionine and S-adenosyl-methionine (SAMe).

The beneficial effects of betaine supplementation on liver metabolism in animal systems, are described in the following recent paper:

Kim SK, Kim YC (2005) Effects of betaine supplementation on hepatic metabolism of sulfur-containing amino acids in mice. J. Hepatol. 42: 907-913.

What are other good sources of betaine in the diet? The USDA has recently compiled a list of betaine contents of a number of common foods:

http://www.nal.usda.gov/fnic/foodcomp/Data/Choline/Choline.pdf

Major plant sources of betaine

Food	mg Betaine/100g of food
Beets (canned)	177
Beets (raw)	129
Bread, whole-wheat, commercially prepared	180
Cereals ready-to-eat, wheat germ, toasted, plain	1396
Spinach, frozen, chopped or leaf, unprepared	675
Spinach, frozen, whole leaf, cooked, microwaved	809
Wheat bran, crude	1507

Clearly, wheat germ and wheat bran are also excellent sources of betaine. But betaine content should not be the sole decision about food choice! As emphasized by several speakers at the conference, it is important for PSC patients to maintain a well balanced diet.

The USDA document above, also lists the amounts of choline in the same foods (choline is readily metabolized to betaine in humans). Choline is a major constituent of the lipid phosphatidylcholine, and so this document also lists the phosphatidylcholine contents of the foods.

For reliable nutrient content data of foods please visit:

http://www.nal.usda.gov/fnic/foodcomp/search/

For those readers interested in learning about the latest advances in diagnosis and treatment of inflammatory bowel diseases, please consult the following abstracts from the recent Falk Foundation Symposium:

Falk Symposium 147

COLITIS: DIAGNOSIS AND THERAPEUTIC STRATEGIES
Birmingham (U.K.)
May 6 - 7, 2005

http://www.falkfoundation.com/pdf/FS147-Abstracts-Internet.pdf

Session I - Diagnosis
Chair:
K. Geboes, Leuven
D.B. Sachar, New York
Role of capsule endoscopy in Crohn’s disease
S. Bar-Meir, Tel Hashomer
Colonoscopic diagnosis of Crohn's disease (CD)
G.N.J. Tytgat, Amsterdam
How, what and when to biopsy
B.F. Warren, Oxford
Traps in the diagnosis of ulcerative colitis
R. Riddell, Toronto

Session II - Microscopic Colitis
Chair:
C. Tysk, Örebro
B.F. Warren, Oxford
Epidemiology
F. Fernández-Bañares, Terrassa/Barcelona
Histological classification
K. Geboes, Leuven
Mechanisms of pathogenesis
J. Bohr, Örebro
Treatment
A. Tromm, Hattingen

Session III - Predicting Outcomes
Chair:
M.A. Kamm, Harrow
M.R.B. Keighley, West Midlands
Predicting the natural history of IBD
S. Vermeire, Leuven
Predicting the outcome of severe ulcerative colitis
D. McGovern, Oxford
Who gets extraintestinal manifestations?
T. Orchard, London
Colitis: Predicting outcomes - who gets cancer?
A. Forbes, Harrow

Session IV - Corticosteroid Therapy
Chair:
J.-F. Colombel, Lille
A. Forbes, Harrow
Why do they not always work?
D. Kelleher, Dublin
Budesonide for ulcerative colitis
A.S. Peña, Amsterdam
How do I use corticosteroids for Crohn's disease?
J. Schölmerich, Regensburg
Why I do not use corticosteroids for Crohn's disease?
J.M. Rhodes, Liverpool

Session V - Azathioprine
Chair:
S. Ghosh, London
A.S. Peña, Amsterdam
Azathioprine: Mechanism of action
M.F. Neurath, Mainz
Pharmacogenetics of azathioprine - useful in clinical practice?
J.-F. Colombel, Lille
When to start and for how long?
M. Lémann, Paris
Azathioprine: Long-term side effects
E.V. Loftus, Rochester

State-of-the-Art-Lecture:
Chair:
T. Öresland, Göteborg
Surgery for ulcerative colitis
N. Mortensen, Oxford

Session VI - Immunomodulatory Therapy
Chair:
S.P.L. Travis, Oxford
A. Tromm, Hattingen
How to use infliximab?
G. D'Haens, Leuven
Biologic agents for ulcerative colitis
C.S.J. Probert, Bristol
Safety of immunomodulation
P. Munkholm, Herlev

Session VII - Cancer and IBD
Chair:
C. Prantera, Rome
J. Satsangi, Edinburgh
Chromoendoscopy
R. Kiesslich, Mainz
Can we prevent cancer by current drugs?
E. Hertervig, Lund
Cancer and IBD: Will molecular understanding help?
P. Desreumaux, Lille
Management of low-grade dysplasia in inflammatory bowel disease
S. Itzkowitz, New York
Low grade dysplasia - what to do?
A.T.R. Axon, Leeds

Session VIII - New Therapeutic Approaches
Chair:
F. Pallone, Rome
E.F. Stange, Stuttgart
Leukocytapheresis
J. Emmrich, Rostock
Helminths
J.V. Weinstock, Iowa City
Probiotics and inflammatory bowel disease
P. Marteau, Paris

State-of-the-Art-Lecture:
Chair:
D.P. Jewell, Oxford
Treatment of Crohn's disease - looking into the future
D.W. Hommes, Amsterdam

The following article is included at the request of Dr. Keith Lindor, Mayo Clinic Rochester, MN

THIS MONTH FROM THE NIH

Primary Sclerosing Cholangitis

Primary sclerosing cholangitis (PSC) is a chronic cholestatic liver disease caused by progressive inflammatory destruction of the intra- and extra-hepatic bile ducts. PSC occurs frequently in the setting of inflammatory bowel disease (IBD), most commonly ulcerative colitis. PSC is estimated to affect 8 to12 persons per 100,000 population and between 2% and 5% of persons with IBD. PSC is more common in men than women, and the average age of onset is 40 years. However, the disease also occurs in children in whom the clinical manifestations and course may be quite different. The etiology of PSC is unknown. Based on its HLA-associations, the high prevalence of auto-antibodies, and its occurrence in persons with IBD, PSC is believed to be an autoimmune disease. However, the typical therapies for autoimmune diseases are ineffective in PSC, and in general, therapy of this disease is unsatisfactory. Ursodeoxycholic acid (ursodiol) is commonly used, but its effects on long-term outcome have not been demonstrated. PSC leads inexorably to end-stage liver disease, and its course can be complicated by the development of cholangiocarcinoma, a highly malignant tumor. PSC now accounts for 6% of adult and 1% of pediatric liver transplants in the United States. Thus, PSC represents an important liver disease with major morbidity and mortality for which current therapies are unsatisfactory. These factors define PSC as a disease of high priority for basic and clinical biomedical research. In the recently published trans-NIH Action Plan for Liver Disease Research:

http://liverplan.niddk.nih.gov

research goals of importance for PSC included development of reliable animal models; initiation of clinical studies to evaluate natural history, etiology and therapy; development of better means of imaging for diagnosis, staging and grading of PSC; and search for non-invasive biomarkers for disease progression and for early detection of cholangiocarcinoma. The current NIH portfolio in PSC includes studies of animal models and both pilot and full-scale clinical trials of therapies. The "High-Dose Ursodiol Trial for Primary Sclerosing Cholangitis" is an investigator-initiated trial comparing the effectiveness of a 4- to 6-year course of high doses of ursodiol (28-30 mg/kg/day) to placebo. A total of 150 adult patients will be enrolled at seven U.S. medical centers. The major endpoints of therapy are prevention of cirrhosis, hepatic decompensation, liver transplantation, and death. Secondary endpoints include improvements in quality of life and histological, cholangiographical, and biochemical features of disease. The principal investigators and study sites include:

- Keith Lindor, Mayo Clinic, Rochester, MN
- Denise M. Harnois, Mayo Clinic, Jacksonville, FL
- M. Edwyn Harrison, Mayo Clinic, Scottsdale, AZ
- Timothy McCashland, University of Nebraska, Omaha, NE
- Velimir Luketic, Virginia Commonwealth University, Richmond, VA
- Alex Befelar, Saint Louis University, St. Louis, MO
- Kris Kowdley, University of Washington, Seattle, WA

To further promote excellence in research on PSC, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) in collaboration with the Office of Rare Diseases and the Morgan Foundation have organized a 2-day research workshop on PSC to be held on September 19-20, 2005 at the Lister Hill Conference Center on the campus of the National Institutes of Health in Bethesda, MD. The focus of the meeting will be to summarize current understanding of the epidemiology, diagnosis and staging, pathogenesis, disease associations, management, and treatment of PSC including use of ursodiol, newer innovative therapies, surgery and liver transplantation. The meeting will also allow for discussion of areas of greatest opportunity for future research. Information on registration and the current agenda for the workshop are available at:

http://www.niddk.nih.gov/fund/other/primarysclerosing/

reprinted from: Hoofnagle JH (2005) Primary sclerosing cholangitis. Hepatology 41: 955 *with slight modifications to the URLs and formatting*

Conference CD

A complimentary copy of the CD will be mailed to each of the conference attendees. Additional copies of the CD ($25 each in the U.S./$30 abroad; this includes shipping and handling) can be purchased from:

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

Please make checks out to: **PSC Partners Seeking a Cure**

Please include your name and mailing/shipping address when you place your order! Thank you!

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We are indebted to all the speakers who contributed to this conference, especially Dr. Gregory T. Everson and his colleagues from the University of Colorado Health Sciences Center.

We also thank all those members of the PSC Support Group, and their family, friends and caregivers, who have generously donated their time and funds to the PSC Partners Seeking a Cure foundation.

Laughter is the Best Medicine

A man with PSC went to a baseball game with his family. They were the best seats he ever had - third row behind the dugout on the 3rd base side. The man became distracted while explaining the rules to his 5 year old son so he didn't see a foul ball come screaming his way. As he turned toward the plate, the ball wacked him on his right side and he fell to the ground in pain.

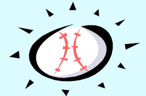
His wife hurried over to him as did some medical people who worked at the stadium. As he lay there clutching his right side, his wife yelled to give him room. "Are you okay, dear?" she asked him over and over.

He sat up gingerly and answered, "I think I'm okay, but I may have a broken rib or two."

"How about your liver, did the ball hurt your LIVER?"

"No, honey. My liver's okay Just in the nick of time, my bile ducked!"

Jason in Cleveland



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Facilitating Contacts Between Conference Attendees

If a conference attendee would like to be placed in e-mail contact with someone else who attended the conference, please write to Ricky Safer (pscpartners@yahoo.com) with your request, and she will forward your message to the person in question.

GUIDELINES FOR SUGGESTING YOUR CITY AS A LOCATION

FOR OUR 2006 CONFERENCE

After our successful inaugural conference in Denver, we are eager to start planning for next year's conference. Before the board makes a decision about the locale for our 2006 conference, we would like to consider your suggestions. If you are interested in hosting the conference, please check on all this pertinent information, fill out this form, and email it to: pscpartners@yahoo.com or fax it to 303 221-0757. We would like to have all forms returned to us by JUNE 15, so that we can start working on the rest of the conference details and get our announcement out much earlier this time. We also want to get an early start writing grants for financial support. If you have any questions, please write to us at pscpartners@yahoo.com

1. Your name/email address/city

2. Advantages of holding the conference in your city

SPEAKERS

3. Who are the speakers who are willing to give presentations? Do you have a verbal/written confirmation from them?

4. Are they local?

5. What topics would they like to present?

6. Are they expecting an honorarium? If so, in what price range?

HOTEL

7. What is the name of the hotel and what group rate has the hotel confirmed for hotel rooms? (Friday/Saturday April 28-29, 2006)

8. How many rooms will they hold for those dates at the group rate?

9. Name/phone number of contact person at the hotel who quoted the hotel rates.

10. How far in advance does an attendee have to cancel the room without paying a penalty?

11. What is the largest number of attendees that can be accommodated in the meeting in the hotel?

12. Is there a charge for the meeting room? If yes, what is the charge?

13. Breakfasts, lunches and snacks must be available on site. Please give us the estimated per person cost for a continental breakfast, box lunch, and snack.

14. Is the following equipment available to rent at the hotel: LCD projector, screen, microphones, podium? What is the cost for these items?

MISCELLANEOUS

15. How far is the hotel from the closest major airport?

16. Describe shuttle service/public transportation from the airport and the cost.

17. How far is the hotel from good medical facilities?

18. Will you be the conference organizer? Do you have other helpers in your city?

Thanks for submitting your city as a possible venue. We appreciate all your input.

Ricky Safer (on behalf of the PSC Partners Seeking a Cure foundation board)