

Providing Education and Support for those with Parkinson's Disease, their families and friends, caregivers and healthcare providers in the greater Austin Community.



CAPITAL AREA PARKINSON'S SOCIETY

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A 501(3)(C) Non-Profit

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June, 2007

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June Meeting

The next meeting of CAPS will be held Saturday, June 16, 2007 at 2:00 pm in the Mc Fadden Auditorium at Seton Main Hospital.

Parking is available in the garage at the south entrance. Free parking vouchers are available at the meeting.

It's been another rough month finding a speaker for the meeting. Maxine Jenks had a nutritionist lined up, but she backed out. Now Maxine's trying to get a pharmacist to come answer our questions about the long list of drugs so intimately involved in treating PD, but as of the date of this publication, all the luck she's had has been bad. Theory has it that it's something to do with Father's Day Weekend.

While simply being in the company of this lively gang should be enough to bring you out, some

might want to check the CAPS Web site calendar for the latest info before you climb into the car on your way to the meeting.

May Meeting Update

Last month's Roundtable session - so named because everyone sat 'round tables and talked over what they've learned about Parkinson's - was, by all reports, well received by all who attended. The opening question was "What about PD surprised you?" and it set the stage for a lot of healthy discussion. According to an on the scene reporter, several members in attendance said they liked the Roundtable sessions better than those with speakers, a good sign that they're finding them useful.

There were some notes taken in this session, and if they turn out useful, we'll put what's available in the online version of this newsletter. The Internet Age. Gotta love it.



CAPS Updates

- Many, many thanks go out to the good people at Parsons House for their kind support of our organization. Not only do they provide us with office space and other help, back on Friday, May 18th, they held a barbecue. In addition to folks loading up on Elgin sausage, ribs, chicken and such with all the fixin's, there was also a cake walk and silent auction . . . with the proceeds going to CAPS! Friday, June 15th, they'll be making the presentation. These folks are good friends indeed.
- Speaking of Parsons House, we're still looking for a volunteer to help out at our office there. At the moment, we're working to get a new member directory out, so this will entail a lot of work on personal computers. Familiarity with Microsoft Excel is a big plus (spelled 'm-u-s-t'). Interested? Please contact us by email at: info@capitalareaparkinsons.org or by calling 512-459-9876 and we'll get you connected.
- And while we're on the subject of volunteers, here's something else you might think about: CAPS is always looking for shiny new faces on its Board of Director. Your insight, knowledge and skills would be invaluable, and you'll get back as much as you give by knowing you're working on a good cause. For more information, please use the email or phone number listed above.
- Last but not least: It's June already, can you believe it? Time certainly does fly when life gets interesting. A lot of important stuff gets forgotten - which is why I include this gentle reminder about CAPS dues. Your 15 dollar contribution will still be appreciated.

Those Once and Future Columns: *The Learning Curve* and *Caregiver's Corner*

You may remember three months ago this wee publication introduced a pair of columns to help our membership cope with PD by sharing the most powerful tool we have: information. At the time, I begged submissions, requested details of the insights you've earned along the way, lessons learned in the long, hard battle with a disease that so literally and fundamentally changes the lives of all it touches. The idea was to share the ingenuity of our members and maybe help our readers find a *eureka* moment or two with alternate solutions to problems old or new. Then I went on to write the first couple months' worth.

In February's *Learning Curve*, I wrote about the process our household had to develop in order to make sure the myriad medications that age and Parkinson's have made necessary are taken as directed, on time and in the right dosage. That same month, I wrote in the *Caregiver's Corner* about the importance of caregivers staying healthy . . . despite of the statistics against us.

The "mailbag" stayed empty. I got many warm (and much appreciated) comments on the change, but nothing to add to the conversation.

In March's *Learning Curve*, I described ways I've discovered to stimulate appetites, how color, textures, presentation and stronger seasonings can offset the effects of Parkinson's-dampened senses of taste and smell. That month, the Caregiver's Corner was not-so-conspicuously absent. There was a lot of other stuff to write about, and my idea well had gone dry.

That month, I got my first input: Lois Rice, CAPS' President, sent me some reflections on the life of a "recovering caregiver," a thoughtful note on the effects of devoting much of one's life to another human being, and how those effects linger after that person has shaken off this mortal coil. I ran her words pretty

much verbatim in April's *Corner*, along with a *Learning Curve* about "blogging" and how keeping a public journal can help one sort things out.

In May, the mailbag was empty again. And this time, so is my head. I'm apparently a three-trick pony.

Now, don't get me wrong. This isn't a self-aggrandizing blurb, a "What a Good Boy Am I" piece. And it's not about how misused I am. I chose this path knowing full well, you, my Gentle Readers, are busy, busy people, and that in the context of your lives, how you cope may not seem remarkable. Necessity mothers inventions, right? No big deal. (Except that it really is.)

What this piece *is* about is a concept I encountered in my former life at a big semiconductor company: the Learning Organization. People learn, that's a given, right? But the idea of an entire organization like CAPS learning? That's a bit trickier. There were a lot of buzz words thrown around back in those days, but it all boiled down to this: an organization - that is, a group of people with common goals and resources - that shares information, no matter how "trivial," could get smarter than the sum of all its members' IQs.

That was the idea behind *The Learning Curve* and *Caregiver's Corner*.

That's still the idea. I've seen it work, but it took insight and knowledge from many sources. From the tiny changes you've made in your day to day life, to the huge, life-altering shifts that rocked your world, if they worked for you, they may work for others. Send them in, be they a couple lines on a napkin or an eight-page email. Let me worry about the editing if you'd like. Just send them. Please?

And, by the way, thanks for listening.

Tom

Parkinson's on the Web

It's been a while since we looked at any news about PD on the World Wide Web, so let's try to remedy that. What follows is a brief intro to each story, and a Web address for those who want to know more. You can type the link into your Web browser, or save the keyboarding and read the online newsletter, with "clickable" links.

Stem Cells: Hope vs. Hype - Salt Lake Tribune - Salt Lake City, UT
Subtitle: *Even if limits were lifted now, a long road to cures remains*
A good, non-technical overview of the state of embryonic stem cell research.
http://www.sltrib.com/News/ci_5999295

Research shows exercise protects against Parkinson's - USA Today
Scientists from three major colleges find that exercise offers a powerful shield against Parkinson's.
http://www.usatoday.com/news/health/2006-01-17-exercise-benefits_x.htm

Pesticides 'up Parkinson's risk'—BBC NewsHealth
Exposure to pesticides could lead to an increased risk of contracting Parkinson's disease, a study has found.
<http://news.bbc.co.uk/1/hi/health/6701269.stm>

University's Parkinson Disease breakthrough—Lancaster Guardian, Lancaster, England
The first ever blood test to detect Parkinson's disease could be on the horizon following research by Lancaster University scientists.
<http://www.lancastertoday.co.uk/lancaster-news?articleid=2920294>

Is it time to embrace those caffeine shakes?—Canada.com

Coffee has its health benefits, but beware the strong brew.

<http://www.canada.com/topics/bodyandhealth/story.html?id=6066e413-3583-48cb-a4d4-0afddd46ac14>

Low-Dose CoQ10 Supplements Won't Ease Parkinson's — Forbes.com

This expensive dietary supplement shows no benefit in low doses.

<http://www.forbes.com/forbeslife/health/feeds/hscout/2007/05/16/hscout604594.html>

Support Group Meetings

For those who can't attend the monthly CAPS meeting, or who would like some extra help with the unexpected life you've found yourself in, here's some additional support.

Austin, TX

Parsons House Pd Support Group

Meetings: 3RD Friday - Monthly - 10-11AM

Location: 1130 Camino La Costa - Austin 78752

Contact : Jaime Eyer 512-454-0524

Deborah Bryson PD Facilitator

Bastrop, TX

Argent Court Assisted Living PD Support Group

Meetings: 4th Thursday - Monthly - 2-3PM

Location: 508 Old Austin Hwy. - Bastrop 78602

Contact : Shasta Martini - PD/Support Group 321-9500 #252

Jenny Bankston - PD Facilitator 252-1512

Burnet, TX

Burnet PD Support Group

Meetings: 2ND Tuesday - Monthly - 1-2 PM

Location: 401 Buchanan Dr./Hwy.29 - Burnet 78611

Highlander Inn / Aim Team Training Center (2 Blocks West of the Highway 29 & 281 Light)

Contact. 512-756-4949 Mark Vidas Directions/Info

New: Cedar Park, TX

The Ranch Retirement Living PD Support Group

Meetings: Last Friday/CALL - Monthly - 1-2PM

Location: 1301 Whitestone Blvd, Cedar Park 78613

Contact : 996-0700 = Directions/Info

Deborah Bryson-PD Facilitator 238-6000

June Young Onset Group Meeting

The Young Onset Group meeting will be held Sunday, June 17th, 2007 at 3:00 PM at the Red Lobster, 109 W. Anderson. For more information, contact James Shrader at 671-3067 or at <mailto:mr12stringjms@aol.com>.

About the Newsletter Staff

This publication is clumsily but lovingly assembled each month by Tom Fisher, <mailto:jumspstart5@sbcglobal.net>. I can be reached at 512-470-2346, but I'm sometimes quite busy and may have to call you back.

