



Inside this Issue

Happy 10th Birthday, PALS Study	1
Staff Overview	2
Participant Overview	4
Impact of PALS Research	1
Sudoku Puzzle	5
CHADD Chapter #477 Upcoming Meetings	5

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# PALS NEWSLETTER

A newsletter of the Pittsburgh ADHD Longitudinal Study

Volume 5, Issue 3

August 2009



## Happy 10th Birthday, PALS Study

The PALS Study is celebrating its tenth birthday! Our first interview was conducted on August 15, 1999. **Since then, we have completed a total of 11,152 visits: 5,011 with young adults and 6,141 with parents.**

**SO, WHAT DOES IT TAKE TO COMPLETE MORE THAN 11,000 INTERVIEWS? WE WONDERED THAT OURSELVES!**

**Each year, we make about 6,500 contacts with study participants**—this includes all of our phone calls, and an increasing number of email that are needed to schedule and confirm appointments, prompt for study paperwork, and review consent forms. In addition, we send out about **7,500 pieces of mail annually**—including holiday and birthday cards, quarterly newsletters, study updates and recruitment letters.

*Continued on Page 2*

## The Impact of PALS Research

The Pittsburgh ADHD Longitudinal Study, or PALS, is now entering its 11<sup>th</sup> year of data collection and its 12<sup>th</sup> year of funding. However, if you consider that this program of research started with the first summer program in 1987, then we are now in our 23<sup>rd</sup> year!



Occasionally we are asked about the results of the study. Not surprisingly, after participating in a study for 10 years you might be curious. Thus, we periodically share study findings in this newsletter. You can read any one of these newsletters on our [www.youthandfamilyresearch.com](http://www.youthandfamilyresearch.com) website by clicking on *Studies*, *PALS*, and then *Newsletters*.

However, in addition to specific findings and publications, sometimes it is helpful to consider the broader impact that a study has on the field in which it conducts its research. At this time, we'd like to share some of the ways that the PALS program of research has affected the field of mental health and more specifically the field of ADHD.

- ◆ The PALS got its start from the Summer Treatment Program for ADHD. Dr. William Pelham, of the University at Buffalo, NY, and the director of the University of Pittsburgh ADD Program from 1987-1996, developed the summer program. The children who participated in this program between 1987 and 1996 are the foundation of the Pittsburgh ADHD Longitudinal Study. The summer program has developed considerably since it began. It was included in a nationally visible research study on ADHD treatment in the 1990s that was conducted at 6 universities in the US and one in Canada. The summer program is now run in more than 20 different locations in the USA. There is even a program being conducted in Japan for the past 5 years, and there are plans underway to start a STP in the Netherlands. The program has been a major force in the field of child mental health in terms of helping parents and treating professionals understand ADHD and its treatment.

*Continued on Page 3*

# Happy 10th Birthday, PALS Study

Continued from Page 1

**So who is making all of those phone calls and stuffing all of those envelopes?!**



There are currently 5 interviewers working for the study in Pittsburgh-- two of whom, **Kellie Spontak** and **Jason Duin**, have been with us since the study's inception and are well known to most of our families.

The additional interviewers are **Beverly Worley**, who recently completed her MSW, **Tara Draper**, who received a Master's in Applied Developmental Psychology from Pitt last year, and **Kendal Kingsley** who is studying for a Master's of Counseling Psychology at Chatham. **Carol Walker** and **Joanne Bethune**, our administrators have also been with the study since it started—joining the program in 1993 and 1996 respectively. In addition to their other responsibilities, Carol edits this newsletter and Joanne handles all of the participant payments. The project is directed by **Brooke Molina, Ph.D.** who joined the ADD Program as a psychology intern in 1992. The PALS study began with a scientist development grant awarded to Dr. Molina in 1996. **Tracey Wilson**, the study's coordinator has been with the ADD Program since 1989 and knew many of our PALS participants when they were children.



**And about those interviewers.....**

Over the course of the past ten years, there have been 23 interviewers who have worked on the project in Pittsburgh, usually 5 - 6 at any given time. Most of the folks who have left have gone on to interesting pursuits and we thought you might like to hear what they are doing now.

**Larissa Souzer** - September, 1997- April, 2000. Neurophysiology Technician, UPMC

**Vanessa Fazio** - June, 1999 - August, 2000. Completed Ph.D. in Clinical Psychology and is a neuropsychologist with the UPMC Concussion Program, and is expecting a baby in November!

**Tammy Lamary** - June, 1999 - August, 2003. Completed a law degree at Pitt and is now an attorney in Erie.

**Lourie Collins** - August, 1997- April, 2003. Living in Beijing, China with her husband and three children (under the age of 5!); She founded and moderates two large Yahoo groups: Beijing Organic Consumers and Beijing Mamas.

**Sara Perez** - January, 2000 - June, 2000. Completed a Ph.D. in Clinical Psychology at Kent State and is currently a Post-Doctoral Research Fellow at the University of Akron and project manager of a PTSD in Battered Women Project.

**Stacy Pomroy** - September, 2000 - October, 2001

is the Assistant Director of Admissions at the Pittsburgh School of Massage Therapy and a new bride.

**Teresa Schmitz** - December, 2000 - July, 2002 is a doctoral student in Clinical Psychology at the University of Maryland, completing a psychology internship at the UC San Diego Medical Center/VA.

**Caroline Boughton** - December, 2000 - January, 2002 is raising a family in Pittsburgh.

**Vicky Krug** - March, 2000 - November, 2005 is an instructor in Developmental Reading and Writing at Westmoreland County Community College.

**Justin Rossini** - September, 2001- August 2003 Completed a Master's degree in Industrial Organization/Psychology at Radford University and is a consultant in the Testing Services Group at Development Dimensions International.

**Renee Weinman** - July, 2006 - March, 2007 is a Research Recruiter in the Department of Medicine, Division of Infectious Diseases at UPMC.

**Erika Greisenegger Zeransky** - January, 2000 - September, 2006 recently moved back to Pittsburgh after coordinating a research study in NYC and living in Dubai.

**Corrie Schoffstall** - July, 2005 - August, 2006 is a Clinical Psychology Doctoral Student at the University of Memphis.

**Liz Jacob Kirstein** - February, 2004 - May, 2007 is doing accounting and administrative work for a small research and development company in North Huntingdon, was married in March of this year and is the proud parent of Roxie, a German Shepard/Lab mix.

**Amanda Thompson** - September, 2001 - April, 2003 is a licensed clinical psychologist at the Center for Cancer and Blood Disorders at Children's National Medical Center in Washington, DC, providing clinical care to children with chronic illnesses.

**Andrea Grana Phillips** - May, 2003 -January, 2006. Completed an MPH at Duquesne University and her law degree from Pitt. She is currently a Presidential Management Fellow with the US Department of Housing and Urban Development in Washington.

**Nate Tatro** - September, 2003-July, 2005 is a Developmental Psychology Doctoral Student at George Mason University and working as an Assessment Manager for the AppleTree Institute for Education Innovation.

**Jessica Casacchia** - October, 2007- April, 2009 Completed a Master's degree in Counseling and is working as a therapist for a community mental organization in Dubois, PA, and planning an October wedding.

# The Impact of PALS Research

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- ◆ ADHD has historically been studied in terms of the symptoms of the syndrome. These symptoms are problems with attention and/or impulsivity and hyperactivity. However, our program of research has strongly emphasized the importance of measuring and studying the day to day functioning of individuals with ADHD and not only ratings of symptoms on a checklist. One reason that this has become especially important, we and others have discovered, is because symptoms of ADHD may become less visible with increasing age, but impairment (problems in daily life functioning, such as underperformance at school or work) may continue for many. As a result, PALS participants and participants in our other long-term follow-up studies are asked many questions about their functioning. We appreciate your patience with this. Our collaborations with other investigators have been strongly affected by this perspective and, as a result of these discussions, quite a few studies in the field of ADHD now emphasize functioning in addition to symptom measurement. Both treatment and follow-up studies have been affected and, as a result, we believe that the development of methods to help people with ADHD maximize their potential are being improved.
- ◆ A related issue is improvement in measurement of behavior and outcome as children age into adulthood. The PALS, as well as a number of other long-term follow-up studies of childhood ADHD, has had to grapple with the need to measure outcome consistently from year to year in order to track change in people's lives. Sometimes questions for one age don't make sense for questions at an older age. For example, asking a child if they've ever had a drink of alcohol is an important question because drinking at a young age is correlated with alcohol problems later in life. However, asking a 21 year old the same question usually seems silly because most people have had a drink of alcohol by the age of 21. So, we add questions about "how often" and "how much" to measure a more important outcome for adults. The PALS study has tangled with the trade-off between asking questions that make sense for one's age with needing to maintain consistency over time in the interview. As a result of this challenge sometimes we have simply written new questionnaires which have been now added to other people's studies. PALS participants also contribute to the interview because the staff bring your comments to our regular meetings. As a result, a number of changes to the interview have been in response to comments by PALS participants. Together these experiences have been

helpful in collaborations and in consultations with other research groups following people over time. An example is that we were asked by the National Institutes of Health a number of years ago to give a talk at a national scientific meeting on the methods of the PALS. Although no study is perfect, and we are always open to suggestions, the PALS study has indirectly contributed to the scientific method of studying people from childhood into adulthood. As a participant in the PALS, you have contributed to that impact on the field of mental health research.



- ◆ It is perhaps plainly obvious that we ask many questions about alcohol, tobacco, and drug use. In the past 10 years, the National Institutes of Health have begun to appreciate that many people who develop problems with alcohol and drug abuse had behavior or school problems in childhood. For these people, childhood difficulties then developed in adolescence to include early drinking, smoking, or drug use, and eventually these experimental behaviors became serious addictions. Not all people who have addictions follow this type of pathway, but many do. Our research has contributed to the NIH understanding that if we can improve children's lives early, we may help to alleviate problems with addictions *for some people*. This has led to a growing understanding that waiting until alcoholism or drug abuse develops in adulthood, and trying to treat it then, may be less effective than also trying to prevent its occurrence in the first place.
- ◆ Many of you in the PALS study were never diagnosed with ADHD (you are in the comparison group), some of you who were diagnosed with ADHD feel that you never had it, and some of you don't connect at all to being diagnosed with ADHD in childhood anymore. For example, you may be doing well and feel that ADHD is something in your past and it's no longer a part of who you are. Quite a few participants see the ADHD as still a part of them and they either still have problems or they have adapted to it. This variability in how our participants are doing and in how they see themselves is an extremely important part of the PALS study. We have realized over time that the outcomes of the children

## The Impact of PALS Research

*Continued from Page 3*

diagnosed with ADHD are quite varied and it is this fact that makes continuing the study so important as the PALS children age through adulthood. As we have interviewed the PALS participants into early adulthood, we have developed a growing appreciation for the need to capture this variability in outcome. This realization may be seen in other long-term studies following children into adulthood and reflected in discussions among investigators at scientific meetings and in our thoughts about how best to analyze our data and think about adulthood outcomes for the PALS participants.

- ◆ Finally, as a result of these varied outcomes and the perspective that day-to-day life functioning is important to consider, we have begun to consider ways that some young adults with ADHD might want assistance in their lives. We have written in previous newsletters (November 2007, February 2008) about the state of the science on adult ADHD treatment and unfortunately not a lot of work has been done beyond testing medication treatments. There are a few small studies but much work needs to be accomplished to develop a range of strategies that might be helpful in small and in large ways, depending upon the interest and needs of the adult.

If you have ideas or suggestions and might be interested in participating in a focus group to discuss strategies for helping young adults, please feel free to email us with your thoughts.

*Brooke Molina, Ph.D.*  
Associate Professor of Psychiatry and Psychology  
University of Pittsburgh  
Co-Principal Investigator of the PALS  
email: [molinab@upmc.edu](mailto:molinab@upmc.edu)



To learn more about the Summer Treatment Program for children, please visit <http://nrepp.samhsa.gov> or Dr. Pelham's website at <http://ccf.buffalo.edu>

## Happy 10th Birthday, PALS Study

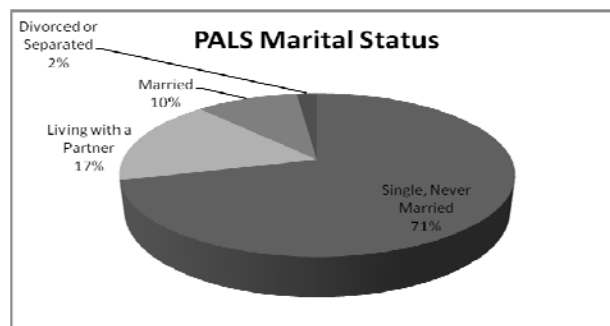
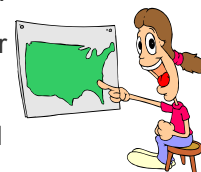
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The study's data are managed in Buffalo, New York, under the supervision of the study's Co-Principal Investigator, **William E. Pelham, Ph.D.** Dr Pelham oversees **Beth Gnagy**, who worked in the Pittsburgh STPs from 1988 to 1996 and has been managing the PALS data since year 1, **Tuma Biswas**, a graduate student in clinical psychology who was an STP counselor in Buffalo for two summers and has helped to coordinate data entry since 2006, and a team of undergraduate students from UB who assist with data entry tasks.

### And how about the study participants.....

Since the study began in August, 1999, we enrolled a total of 604 participants who are now young adults: 540 males and 64 females. Currently, 26% of the participants are ages 20-24; 52% are ages 25-29; 22% are ages 30-35. Of the total enrolled, 569, or 94% have remained in the study. Only 25 participants have dropped out and sadly, 10 have died.

Not surprisingly, three quarters of our participants still live in Pennsylvania, 90% in the greater Pittsburgh area. 24% of our participants are scattered across the country, with the most commonly lived in states being Florida, California, Ohio, North Carolina, New York, Maryland, and Virginia. 1% of the entire sample lives overseas - in Australia, Italy, Scotland, Germany, Iraq, Spain, U.K., Korea and France.



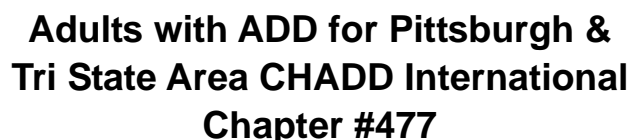
Roughly half of the young adults in the study are living independently with roommates, significant other, or their own family; 40% are living with their parents, and the remainder live at school or in the military.

### And how about the next generation?!

So far, there are 147 children of the PALS participants!








For more information, please contact Leslie Stone  
at 412-682-6282 or visit [www.pittsburghhadd.org](http://www.pittsburghhadd.org)

As we go to press, we aren't sure what the exact impact of the G20 summit will be on our operations in Oakland.



 We do know that summit functions will be held in nearby Phipps Conservatory of the afternoon and evening of Thursday, September 24 and the city has granted a permit for a protest parade beginning in Oakland at noon on Friday, September 25. The PALS study will be fully operational on both of those days, but we have elected NOT to offer subject visits in Oakland on either of those days. Staff will be available to answer the PALS line, 412-246-5656, and to schedule appointments, conduct phone interviews, etc. We will offer office visits again beginning the morning of Saturday, September 26th.

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From our home page on the website, select *Studies*, click on *PALS*, *Newsletters* and you will see *Sudoku Puzzle Answer Key*.

PALS Study-Molina  
University of Pittsburgh  
200 Meyran Building  
Suite 400  
3811 O'Hara St.  
Pittsburgh, PA 15213

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