

weap: The People

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Secretin: The Magic Bullet that Wasn't

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Wisconsin Early Autism Project

There has long been a suggested link between autism and digestion. This possible connection has been explored with pharmacological as well as therapeutic treatments.

In 1996, after almost 2 years of near constant diarrhea, an autistic boy named Parker Beck had an endoscopy at the University of Maryland. During his stay there he was treated with, among other things, secretin.

Secretin is a naturally occurring hormone that produces bicarbonate which neutralizes acid in the stomach. Secretin is most commonly used to test for pancreatic enzyme production necessary for proper digestion. Initially harvested from pigs, it was eventually created synthetically.

Soon after his treatment, Parker's digestive and behavioral problems improved and his mother Victoria began speaking out about secretin as a cure for autism.

Support of the Director of Autism Research Institute in San Diego, Bernard Rimland, Ph.D. and the following

continued on page 2

INSIDE THIS ISSUE

- 1 U.S. Senators
- 1 Secretin
- 2 Santa comes to WEAP
- 3 Groups and Classes/Employment Opportunities
- 4 Legislative Contact Record

U. S. Senators Ask for Autism Research

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A-CHAMP Parent-Advocates Meet with Senator John McCain in the Russell Senate Office Building; Left to Right: Char Baldrige (Virginia); Linda Wessels (Iowa); NoMercury's Lujene Clark (Missouri); Senator John McCain; Bobbie Manning (NY); Julia Whiting, M.D. (Va.); John Baldrige (Virginia)

WASHINGTON, D.C. – On December 7, 2007 Senators John McCain (R-AZ) and Joe Lieberman (I-CT) formally requested that the Senate Committee on Health, Education, Labor and Pensions (HELP) hold hearings into federal research efforts on autism causes and treatment. The Senators' letter specifically requested attention to environmental factors that may cause autism, including thimerosal.

In their letter to HELP Committee Chairman Ted Kennedy (D-MA) and Ranking Member Mike Enzi (R-WY), Senators McCain and Lieberman state,

Families of children with autism and their health care providers depend on the federal autism research agenda in hopes of preventing future cases and identifying effective treatment methods. We have heard

continued on page 3

Dateline NBC news piece telling the Beck's story captured national attention.

In 1999, the National Institute of Child & Health Development, a division of the National Institutes of Health, reported on a study they sponsored which then appeared in the December 9th edition of The New England Journal of Medicine. The conclusions were characterized by NICHHD as "secretin offered no more benefit for children with autism than did treatment with a placebo."

Despite these early trepidations, in 2001 the FDA granted "Fast Track" status to the study of secretin as a treatment for autism.

The Cochrane Collaboration, an international medical review group, conducted an analysis of 13 studies on the effects of secretin on children with autism and concluded that "There is no evidence that single or multiple dose intravenous secretin is effective and as such it should not currently be recommended or administered as a treatment for autism."

Their explanation for some previous positive results is that those tests relied too much on anecdotal evidence provided by parents and non-standardization of outcome measures. In the end any benefits attributed to secretin were also present in groups of children only administered a placebo.

So what went wrong? How could a wonder drug be discovered, tested with some positive results and then dismissed just as quickly?

All of us have hope, and sometimes that hope leads us down blind alleys. We want autism to end. We want the number of afflicted children to decrease. We wait for a day when autism is an historical footnote in the annals of medical history.

It would be grossly irresponsible for any of us to ignore a possible breakthrough. Although WEAP did not sponsor an official study, many of our clients tried secretin hoping it would make a difference. Unfortunately they were disappointed, as were we.

Hopefully a cause or combination of causes will be discovered and a medical or pharmacological treatment can begin. Nothing would make us happier.

In the meantime, behavioral therapy has been replicated over and over again as a proven and effective treatment for autism. Everyone involved with us, employee and client alike, are working hard to make a difference in the lives of children and families affected by autism. Together we are accomplishing things that families the world over are looking for. We're glad to have you here on the frontlines of autism treatment. ♦

Santa comes to WEAP

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A happy Christmas encounter for Mrs. Claus, Connor Mayhew, Santa Claus and Bronwyn Mayhew

On Wednesday, Dec. 19th, Santa and Mrs. Claus made a scheduled appearance at the Madison WEAP office. The annual Santa Party gives the opportunity for many local children to meet the jolly couple.

When asked to comment on why he is sure to make this stop every year, Santa replied "These children are very dear to me. They've worked all year to be good little boys and girls. When they sit next to me and tell me what they want for Christmas, it's just as great a thrill for me as I hope it is for them."

Dr. Sallows agrees. "Our children are WEAP's strongest asset. Without them and their hard work we wouldn't even exist. Anything we can do to bring a little more love and attention their way, we are happy to do. Santa has been very gracious in making an appearance every year and I can't wait for his next visit."

Children were greeted at WEAP's door with goody bags filled with treats and toys handed out by helper elf Mary Johnson.

Other Santa's helpers Abby Meinen, John and Lynn Thompson, Jill Lins, Kathy Schutt, Matt Sergeant, Susan Thomforde, Gail Reed and Dan Graupner helped set up and operate the various activities at the Santa Party.

Cookies, including those of the cassein and Gluten free variety, were available as well as juice boxes and other treats.

Children and their parents experienced leisurely visits with Santa. Other fun to be had included face painting, decorating cookies, making Christmas ornaments and

continued on page 3

telling New Year's resolutions.

Our guests sat next to Santa, oftentimes giving him hugs, and let their Christmas wishes be known. Polaroids were taken and given free of charge in a special Christmas frame.

5-year-old Braiden Hengst brought Santa a cookie in exchange for inside information. He was curious about the number of reindeer under Santa's care. Once he got an answer he was quick to report his findings to mother Heather.

Santa continues "I was just at your Milwaukee clinic last week and the boys and girls there really brightened my day as well. I love all children but seeing WEAP's youngsters year after year and seeing their progress is extra special."♦

Know your Representative

You can find your state legislators with the following link. Please use it to contact them and let them know how important autism funding is to you and your family.

<http://waml.legis.state.wi.us>

the concerns of many Americans that a number of environmental exposures, such as thimerosal, pesticides, metals, organic pollutants and other ambient factors, may be linked to autism. Our research efforts should support broad approaches to understanding the wide range of etiological factors in our environment that may be related to autism for both prevention and treatment purposes.

A-Champ, a national, non-partisan support organization for children with neurodevelopmental and communications disorders, along with some parents and grandparents of children with autism, visited Sen. McCain in Washington, DC on November 20, 2007.

"We applaud Senators McCain and Lieberman for taking the lead on this important issue" said Mary Webster, a member of A-CHAMP's Board of directors. "[We] urge members of the Senate HELP Committee to begin hearings on this matter without delay."♦

Groups and Classes

Location	Group	Age/Level	Facilitator	Fee	Days	Time	Start Date
Madison	Play Group	3 + YRO	Ariel	\$30/session \$240/8 sessions	Wed	12:00-2:00PM (1.5HR)	End of Jan.
Madison	Sibling Class	Open to Community 8-14	Chris W Michelle S	\$30/session \$4/child daycare (register 2 wks in advc.)	Tues	4:00PM	Feb. 5
Madison	Peer Interaction Skills	Open to Community	Chris W	\$30/family	2 nd Tues ea.Month	4:00-5:30PM	Feb. 12
Madison	Teen Group	Open to Community 12 + YRO	Matt N	\$40/session	Thurs E/O Is outing	4:00-6:00PM	continuing
Green Bay	Caregivers Group	Open to Community	C. Van Dyke	\$30/session \$4/child daycare (register 2 wks in advc.)	Mondays	5:00-6:15PM	Feb 4- May19
Milwaukee	Kid's Group	9-12	Maggie D.	\$30/session	Mon	4:30-6:00PM	Jan. 28
Milwaukee	Parent Training	N/A	Alissa M	\$60 for 3 class sessions	Tues	4:30-6:00PM	Feb. 5,12,19

Current Openings

GREEN BAY 920-338-1610	MILWAUKEE 262-432-5660	Wauwatosa West Allis New Berlin Muskego Oconomowoc Waukesha Sussex Pewaukee Mukwonago	Iron Ridge Juneau Milwaukee Slinger Kewaskum Ixonia	MADISON 608-288-9040	EAU CLAIRE- LA CROSSE 608-781-6500
Sheboygan Manitowoc Oneida Luxemburg	Bristol Cudahy Kenosha Oak Creek Racine			Madison Baraboo Cobb Sun Prairie Watertown Lake Mills	Independence Eau Claire

LEGISLATIVE CONTACT RECORD

Date: ____ Jan. 6, 2008

Your name: _____

Legislator's name: _____ District: _____

Method of Contact:(Check one) ___ Email ___ Phone ___ Letter ___ In Person

Hello, my name is _____ and I am one of your constituents here in _____. I am (emailing, calling, writing, talking) to you today about **INSURANCE COVERAGE FOR AUTISM** to ask for your support of Senate Bill 178.

- Research done here in Wisconsin shows that 50% of children treated are able to enter 1st grade with little or no need for supportive services.
- For every \$1 dollar spent toward therapy the public tax payers save \$19 dollars in long term care costs for untreated individuals.
- The cost of paying for untreated people who are diagnosed with autism is increasing.
- The CDC reports that 1 in every 150 children born in America will be diagnosed with some form of autism.
- ABA therapy has helped my child overcome so much (list behaviors, attention, reading, speech, tell your child's story).
- My child deserves to have autism treatment covered by insurance.
- My child deserves the chance for a happy, healthy life. ABA therapy is his/her best chance at achieving that.
- The current system restricts hours and restricts progress.
- I want to know that you are willing to stand up to the insurance companies in the name of my child and all families in Wisconsin.

As one of your active constituents I am asking you to vote YES FOR SB 178.

Legislator's Response: (did your representative say YES or NO?) _____

Thank you for making contact with your legislator. Your goal is to contact your legislator about supporting the Insurance Senate Bill 178 through phone, email, and snail mail in order to make the best impression. Ask your friends and family to use this script also to do the same.

PLEASE EMAIL THIS PAGE TO: amasek@wiautism.com; jilins@wiautism.com