

BREAKTHROUGHS

Partnership for Cures 70 West Madison Street, Ste. 1500, Chicago, IL 60602

UW Madison Scientists Team with Rockford Chapter Philanthropists to Repurpose Technology for MS Patients

What happens when you mix cutting edge technology, creative researchers, and dedicated philanthropists? You might get a miracle treatment for patients! Partnership for Cures staff, scientists Kurt Kaczmarek, Yuri Danilov and Mitch Tyler at UW Madison's Tactile Communication and Neuro-rehabilitation Laboratory (TCNL), and PFC Rockford Chapter committee co-chairs and lead donors Terry and Al Provenzano are in the midst of creating such a miracle.

Several years ago TCNL scientists wondered if they could create a technology to help the blind "see" by substituting other nerves for the eye nerves to collect the visual input. The research team used a small video camera attached to a set of miniature electrodes that stimulated the millions of nerve endings on the tongue. A blind subject wore a camera that was able to "see" a doorway. That picture of the door was sent as a pattern of electrodes that felt like soda bubbles bursting on the tongue. The tongue then sent the "picture" to the brain. The subject was able to guide himself by "seeing" the door with his tongue.

Serendipity happened when scientist Mitch Tyler got an ear infection and lost his sense of balance. He needed something to re-train his balance, so he hooked up a device to the tongue stimulator that helped his tongue sense when he was tipping left or right, or forward or back. This device helped him re-learn to keep his balance. A new use for the technology was born! You can see a video of the vision and balance miracles at http://www.pbs.org/kcet/wiredscience/video/286-mixed_feelings.html



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From Left: Dr. Yuri Danilov- Neuro-modulation and Rehabilitation at the Tactile Communication & Neuro-rehabilitation Laboratory (TCNL) at UW-Madison; Terry Provenzano-Chair, Rockford Campaign Committee; Dr. Kurt Kaczmarek- Administrative Director, TCNL; Al Provenzano-Board member, Rockford Chapter; Mitch Tyler-Sensory Substitution and Clinical Studies, TCNL



In May 2008, Al and Terry, Al's MS physician Dr. Chris Luzzio, and PFC's Dr. Bruce Bloom took a trip to UW Madison to meet with the TCNL scientists with the hope of the possibility that the technology would provide help for Al with the balance and gait issues related to Multiple Sclerosis. Al agreed to be a test subject for the treatment which is known as Non-invasive Neuro-modulation. As a result of the Wisconsin visit and Al's anecdotal success, PFC's Rockford Chapter agreed to fund a \$77,000 human clinical trial at the TCNL Lab to test this repurposed technology on 10 MS patients. The trial will determine how the technology can help patients regain mobility, balance and energy lost to nerve and muscle damage. This project is co-funded by donors of UW Madison and is set to begin in late summer of 2008.



Dr. Danilov guides Al (with the "Balance Hard Hat" on and tongue stimulator in his mouth) as he re-learns how to keep his balance with his eyes closed using this UW Madison technology. Mitch Tyler monitors the computer that collects the data on Al's progress.

Teaching Old Drugs New Tricks!

Pharmaceutical companies spend upwards of \$1 billion to bring a single drug to pharmacy shelves! If they find a drug that works, but the molecule has never been tested in humans, it might require as many as 15 years of testing. At the current rate of discovery, it will take decades for new drugs to get to patients, AND MOST CAN'T WAIT THAT LONG!

Partnership for Cures focuses on finding and funding repurposing research, a fast, safe, inexpensive way to quickly impact the lives of patients. Teaching an "old drug new tricks" eliminates the cost and time issues of new drug development. It gets treatments to patients quickly and cost effectively.

Others see the benefits of teaching old drugs new tricks. Curtis Chong, a 31-year-old pharmacologist at Johns Hopkins, is spearheading an innovative way to find new uses for old drugs to help the developing world. The Johns Hopkins Clinical Compound Screening Initiative is an open-source effort to collect and index more than 10,000 known medications and determine which of them are also effective against hundreds of low-profile, Third-World killers. The library will function something like a Wikipedia of drug discovery where scientists around the world can contribute to the database and even provide samples or screen drugs themselves, thereby saving millions of dollars on R&D. By 2011, Chong hopes to test every pharmaceutical on the market, with the aim of bringing more affordable treatments to the people who need them most. The index will include a collection of the scientific and medical literature, patents, FDA filings, and previously unpublished data from drug companies and academic labs.



Curtis Chong, center, with David Sullivan and Jun Liu, has already identified potential new uses for 3 FDA-approved drugs.

Harvard Teams with Friends United Again to Fund Two Diabetes Trials

In 2003, Dr. Denise Faustman of Harvard/Mass General Hospital in Boston discovered that Type 1 diabetes can be permanently reversed in mice through manipulation of their immune systems. To make sure this discovery had a chance to become a cure, Partnership for Cures brought Dr. Faustman and Friends United for Juvenile Diabetes Research (FUJDR) together to establish a partnership that was leveraged with a larger grant from the Iacocca Foundation. Friends United is a local Chicago-area grass-roots organization that began as a small group of friends with a mission - to help fund research to cure juvenile diabetes.

In 2008, Dr. Faustman and FUJDR have joined forces again. With a sizable grant from Friends United the Faustman Lab will move forward on translating their discoveries into human clinical trials. A Phase I trial began at Mass General in January in type 1 diabetic volunteers and will set out to determine whether treatment with Bacillus Calmette-Guerin (BCG) temporarily induces high levels of tumor necrosis factor-alpha (TNF- α) to eliminate one population of abnormal white blood cells in patients with type 1 diabetes. This FDA-approved trial is expected to take 18 months to complete. Dr. Faustman and her team hope that this trial will show that BCG is safe and promising as a drug to eliminate one population of defective cells in type 1 diabetes. If successful, they will advance this drug into Phase II trials. This portion of the project will receive \$10,000 of the total FUJDR grant.

The FUJDR grant will also fund a clinical screening program to find other existing generic drugs that can fight autoimmunity. Since generics are already manufactured using clinically approved FDA standards, expensive manufacturing processes and

approvals do not need to be initiated. Overall, these advantages could lead to a shorter timeline and smaller budget for new treatments to reach patients. If successful, this project would allow the first screening of human white blood cells with generic drugs that may have usefulness in a new disease indication.

"This support is critical and we are grateful to Partnership for Cures for their continuing enthusiasm in matching us with interested donors." Dr. Denise Faustman.

LUNgevity Expands PFC Partnership

Dr. Bruce Bloom, Partnership for Cures Chief Science Officer, was recently invited to join the LUNgevity Foundation's Medical Advisory Board. The LUNgevity Foundation is a long-time PFC partner and this adds a new dimension to the relationship. LUNgevity Foundation's mission is to save lives and ease the burden of lung cancer on patients and their loved ones. Find out more by visiting them at www.lungevity.org.



PFC Teams with London-based Myrovlytis Trust

The Myrovlytis Trust ([MT](#)), a medical research charity based in London, was created in late 2007 with two goals in mind. The first goal of the organization is to promote research into rare genetic disorders, including Birt-Hogg-Dubé (BHD) syndrome. The Trust's second goal is to advance education of the public in medical and molecular genetics.

In May, John Solly, Charity Manager of the Myrovlytis Trust (www.myrovlytistrust.org), contacted Partnership for Cures about working together to find a cure for BHD. Myrovlytis Trust has the funds and a science board and PFC has the experience finding, vetting and managing research. The two organizations decided that in September of this year, they will send out a Request for Proposal (RFP) asking researchers to generate ideas that will produce better treatments or cures for patients with BHD. This program will offer up to four one-year Pilot Grants at \$25,000 each. PFC and MT believe that clinicians and research scientists around the world have scientific and clinical insights, patient anecdotal results, new scientific knowledge, and research skills that could impact BHD patients immediately through repurposing research.

Birt-Hogg-Dubé syndrome is a rare disorder that affects the skin and lungs and increases the risk of certain types of tumors. The condition is characterized by multiple noncancerous skin tumors, particularly on the face, neck, and upper chest. These growths typically first appear in a person's twenties or thirties and become larger and more numerous over time. Affected individuals also have a higher chance of developing cysts in the lungs and an abnormal accumulation of air in the chest cavity that may result in the collapse of a lung. Additionally, people with BHD syndrome have an increased risk of developing cancerous and noncancerous tumors in other organs and tissues.

For more information about the RFP, or to create a Pilot Grant Program around a disease of interest to you, contact Dr. Bruce Bloom by email at Bruce@4cures.org or by phone at (3123) 601-8856.

Myrovlytis Trust aims to advance and promote research into medical and molecular genetics in order to better understand, diagnose, prevent, cure and relieve conditions caused by genetic disorders and/or diseases including but not limited to Birt-Hogg-Dubé syndrome and the free dissemination of the results of such research to the public.



Bringing Scientists and Philanthropists Together

On May 15th 2008, Partnership for Cures held a Pediatric Cancer Symposium attended by foundation representatives and individuals wanting to learn more about how to make a difference in funding the war on kid's cancers. The event was generously hosted by The Private Bank. Presenters included Drs. Marilou Schmidt, Head of Pediatric Oncology at UIC, Stewart Goldman, Neuro-oncology Director, Northwestern University, Steve Kron, Assoc. Professor Genetics and Cell Biology, University of Chicago and. Kathleen Casey, President of Bear Necessities Pediatric Cancer Foundation. "All of these presenters were chosen for a specific reason. Each brought a different element of the reality of pediatric oncology to the table, much like a piece to a puzzle" said Deirdra Lucas, Director of Partnership Development for PFC. At the end of the presentation portion of the event, a question/answer/discussion took place over a delicious lunch.

Childhood cancer is the leading cause of death by disease for children under 15 years old (greater than HIV, heart disease, cystic fibrosis, and infection combined). The current goal in pediatric oncology is to improve the survival rates and to reduce the immediate and long-term side effects of the disease including second cancers, cognitive deficits, musculoskeletal abnormalities, major organ dysfunction and infertility.

The donors and scientists of Partnership for Cures support medical research that can most *quickly* lead to medical breakthroughs for disease. We can do this for pediatric cancer with your help. A gift from you will fund the science that will have an immediate impact on the lives of children afflicted with cancer while they are still able to benefit.

Lung cancer is the leading cause of cancer death in the United States. Lung cancer kills more Americans each year than prostate, breast, colorectal, and pancreatic cancers combined.

FDNOW Fundraisers a Success!

FDNOW at Partnership for Cures held its first annual online auction from March 7-17, 2008. Hundreds of people logged on to browse, shop, bid and vie for over 200 fun, functional and trendy items including a GPS, diamond studs and a Flip Video. This entertaining 10 days of excitement raised almost \$20,000 to fund a cure for the childhood killer Familial Dysautonomia (FD).

On May 12, 2008, The Sixth Annual David Z. Herman Memorial Golf Classic and Gala Dinner in Oceanside, New York, raised over \$200,000 to benefit FD NOW at Partnership for Cures. The event attracted over 100 golfers and over 200 dinner guests. The day-long fundraiser memorializes David Z. Herman, whose 3-year old granddaughter is afflicted with FD. At dinner, Drs. Berish Rubin and Sylvia Anderson presented an update from the Laboratory for Familial Dysautonomia Research at Fordham University in New York. This was followed by a raffle drawing and silent auction. David's granddaughter, along with hundreds of others afflicted with FD, continue to benefit from this lab's discoveries, which include two natural compounds and a nutritional regimen. Funds from this event will accelerate this lab's progress. The next breakthrough is expected in two years or less.



Golf-outing attendees: David Z. Herman's relatives (left), Jeff Goldstein (father to 12-year old with FD), Drs. Rubin and Anderson from the Laboratory for Familial Dysautonomia Research at Fordham University and Ann Slaw, Chair of FD NOW at PFC and mother to a 16-year-old with FD.

“Matchmaking Medical Miracles”

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Visit us at: www.4Cures.org

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