

## Powerful Patient 2008 week 38

Host: Joyce Graff, WebTalkRadio.net

### The Silent Disabilities: Brain Development and Injury

With autism increasing, and with veterans returning from Iraq with invisible but very real brain injuries, we need more understanding and constructive action toward people with intellectual and developmental disabilities. With early intervention and appropriate treatment, there is hope that people can live valued, respected, independent lives.



Leo Sarkissian

#### 1) About Our Guest

**Leo Sarkissian** has served at The Arc of Massachusetts as its executive director since November 1991. The Arc is a grassroots organization of parents, professionals, people with specific developmental disabilities, and concerned individuals. There are 22 affiliates, often called Arcs in Massachusetts, each with its own board of directors and mix of services. They participate in advocacy and educational goals on behalf of 120,000 individuals with specific developmental disabilities in the state. See <http://arcmass.org>

Leo advocates for the people with intellectual and developmental disabilities and the state and local levels. He meets with key government decision-makers and represents The Arc in the media. During his tenure, The Arc of Massachusetts has been involved in campaigns that resulted in new funding for services such as Turning 22, the Waiting List and Family Support.

Leo has been the editor of the handbook, *Building a Future*, which was written to inform families and individuals with developmental disabilities about options for independent and staff-assisted housing. He serves on the Resource Committee of The Arc U.S.

Leo responds to the comments made by Michael Savage on his radio show disparaging people with autism.

#### 2) About Autism

For additional information about autism, see

<http://www.autism.com>

<http://autismspeaks.org>

<http://www.autism-society.org>

A link between vaccinations and autism was proposed in 2001, but has not been proved. The most suspicious ingredient was thimerosal, a derivative of mercury, which was used

as a preservative in some vaccines. At this point, thimerisol has been removed from nearly all vaccines. See <http://www.fda.gov/cber/vaccine/thimerosal.htm#tox>

The Environmental Working Group conducted a study in 2005 to assess the “body burden” of newborns. They tested umbilical cord blood from 10 randomly selected infants and found that an average of 200 industrial chemicals and pollutants had crossed the placenta. The list includes substances such as mercury, pesticides and perfluorinated chemicals (PFCs), which are the active ingredients or breakdown products of Teflon, Scotchgard and other fabric and carpet protectors, and food wrap coatings. All of these are linked to birth defects and developmental issues, as well as to cancer. See [http://www.autism-society.org/site/DocServer/EH\\_leaded\\_with\\_toxins.pdf?docID=4841](http://www.autism-society.org/site/DocServer/EH_leaded_with_toxins.pdf?docID=4841)

### **3) About Traumatic Brain Injury**

Traumatic Brain Injury (TBI) can be caused by hitting the head – sports injuries, automobile injuries, falls, or even surgeries. Impact or disturbance of brain tissue can have lasting effect that may take months or years to improve. The injured person may not even have a visible bruise – the bruise is to the brain tissue.

“As of April 2007, about 1,800 U.S. troops, according to the Department of Veterans Affairs, were suffering from traumatic brain injuries (TBIs) caused by penetrating wounds. But neurologists worry that hundreds of thousands more -- at least 30 percent of the troops who've engaged in active combat for four months or longer in Iraq and Afghanistan -- are at risk of potentially disabling neurological disorders from the blast waves of improvised explosive devices (IEDs) and mortars, all without suffering a scratch. ... For the first time, the U.S. military is treating more head injuries than chest or abdominal wounds. ...

“Here's why IEDS carry such hidden danger. The detonation of any powerful explosive generates a blast wave of high pressure that spreads out at 1,600 feet per second from the point of explosion and travels hundreds of yards. The lethal blast wave is a two-part assault that rattles the brain against the skull. The initial shock wave of very high pressure is followed closely by the "secondary wind": a huge volume of displaced air flooding back into the area, again under high pressure. No helmet or armor can defend against such a massive wave front. ...

“What's baffling is the Pentagon's failure to work with Congress to provide a steady stream of funding for research on TBIs. ... Soldiers face a struggle to get the long-term rehabilitation necessary for a TBI. At Walter Reed, Macedo said, doctors have chosen to medicate most TBI patients, even though cognitive rehabilitation, including brain teasers and memory exercises, seems to hold the most promise for dealing with the disorder.”

From “A Shock Wave of Brain Injuries,” by Ronald Glasser, M.D., *Washington Post*, Sunday, April 8, 2007. [http://www.washingtonpost.com/wp-dyn/content/article/2007/04/06/AR2007040601821\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2007/04/06/AR2007040601821_pf.html)

See also <http://www.birf.info/home/library/vet/vet-tbi-iraq.html>

On September 28, 2008, the Powerful Patient will interview a company with a new technology designed to assist in the rehabilitation of cognitive abilities.

#### **4) About Special Needs**

About a year ago we spoke with two mothers of special needs children. One of the things they said was that in addition to the day to day challenges of working with their children, they had to deal with the prejudices and misconceptions of the parents of the other children. They ask all parents to understand them better, and help to include all children in school activities and play dates.

[http://www.powerfulpatient.org/archive/2007/07d\\_special\\_needs.php](http://www.powerfulpatient.org/archive/2007/07d_special_needs.php)

#### **5) About the national ARC**

The Arc U.S. is the world's largest community based organization of and for people with intellectual and developmental disabilities. It provides an array of services and support for families and individuals and includes over 140,000 members affiliated through more than 850 state and local chapters across the nation. The Arc is devoted to promoting and improving supports and services for all people with intellectual and developmental disabilities.

Local chapters of The Arc come in every shape, form and size – from small voluntary groups to large and sophisticated multi-million dollar organizations, like the one in Massachusetts.

The Arc's vision is that every individual and family affected by intellectual disability in the United States have access to the information, advocacy, and skills they need to participate as active citizens of our democracy and active members of their community. It works to ensure that people with intellectual and developmental disabilities and their families have the supports they need to live an ordinary, decent American life:

- People with intellectual and developmental disabilities and their families are valued, respected and included in all communities.
- People with intellectual and developmental disabilities direct their own lives. People choose their services and supports from many available sources.
- People are empowered through nonprofit advocacy. State and federal governments administer programs and set budgets that meet everyone's needs.

For more information and a guide to resources, see <http://www.thearc.org>

#### **6) Unmet Needs Survey**

The ARC of Massachusetts has a survey open to collect information from both children and adults with disabilities. Please feel free to complete this survey.

Introduction from the Arc: "The survey aims to identify your most important and desired support needs. We have set up categories across a variety of life activities such as health,

transportation, social needs and employment. We request some background information so that we can group results by different age groups and geographic regions.

“We trust that this survey will help us understand the kinds of assistance or supports that the individual needs to live well in his or her community. After collecting this information, we will develop a summary which will be published on-line and used to advocate with policy makers. Your participation in this survey will not only help you or your family member but others who have needs but who are unable to participate. Results will make a difference in our ability to obtain new services. All answers will remain confidential”

[http://www.surveymonkey.com/s.aspx?sm=wfMywXu402wOVjvnrMuGkw\\_3d\\_3d](http://www.surveymonkey.com/s.aspx?sm=wfMywXu402wOVjvnrMuGkw_3d_3d)