

The Harbinger Supplement: Disabilities

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Letter from the Editor

Dear Readers,

The connectedness within the Health Science Department reflects the richness that permeates this campus. Advocates of cultural sensitivity and civil liberties continue to advance us on the health continuum. Additionally, the following poignant stories by our peers reflect the vocal kaleidoscope that represents our community.

It is my pleasure to introduce this Supplement Section to *The Harbinger*. As we embrace our differences, may we bridge existing gaps, as well, in the movement towards change.

Yours,
Maytal Bar-shir
Editor-in-chief

Living with Cystic Fibrosis: Hope in the Face of Hardship

By Editor Maytal Bar-shir

To some people, being out of breath is an acute hindrance. To MPH Student Lara Borowski, it is a reality of dire straits.

Borowski is one of 30,000 Americans in the United States living with cystic fibrosis (CF). CF is a complex chronic genetic disease that slowly deteriorates the lungs. The deterioration comes from chronic infections similar to pneumonia, and prevents enzymes in the body from breaking down food. Over time, the condition leads to respiratory failure.

"When I got really sick, in 2002, my lung capacity dropped down to about 30% of normal," says Borowski. The most debilitating symptoms of the condition hit our peer at 22. That's when she also experienced the onset of cystic fibrosis-related diabetes, requiring insulin shots with food intake. Susceptible to infections, and rapidly losing both body weight and oxygen, Borowski had to wear a round-the-clock oxygen nasal tube (cannula). "It was pretty much hell," she says.

It took Borowski three years before wholly committing herself to lung transplant surgery, a life-altering procedure. Arriving at almost five years post surgery now, Borowski is halfway to what is considered the median life expectancy for lung transplant recipients.

The success of the surgery is reflected in Borowski's everyday quality of life: "It's given me more hours to be able to function through the day. I'm back in school, I have an active social life again, and I exercise," she says. Not many people realize how crucial exercise is to Borowski; it assists in clearing her lungs.

Onward and upward, last summer, she competed in the U.S. Transplant Olympics in Pittsburgh, PA: "I did a swimming relay and I'm a terrible swimmer." After agreeing to do the backstroke only, Borowski met the pool, "wearing a feminine-looking speedo." Following a sudden five-minute panic attack and an awkward practice lap without goggles, she somehow pulled a perfectly straight line during the competition, helping her medley team win the gold. "Go figure," says Borowski.

Since her life-altering flare-up in 2002, Borowski has also become adept at navigating the healthcare pool. She uses her voice to accentuate her capacity to understand and partner in her health care. "You always have to question things," she contends. "I teach myself what everything is and what it means and does...because doctors aren't gods."

For future health professionals, Borowski underscores the importance of recognizing the patient who is disabled: "Look more for what the person is able to do rather than what they're not able to do. Instead of just seeing the obvious disability, look past it...to see the ability."

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Lara Borowski — Pre-Surgery
Photos courtesy of Lara Borowski

Lara Borowski — Post-Surgery

Living with Pain

By Correspondent Michele Mashburn

Someone lightly brushes against you and it hurts. You have just woken up from a night's sleep, yet you feel like you haven't slept at all. Concentration impaired, you're walking in a fog, struggling with long and short-term memory, and a constant cognitive overload. Your symptoms often misunderstood, you are told that "it is all in your head." This is fibromyalgia and one out of 73 Americans are diagnosed in the United States each year, according to the National Institutes of Health.

Fibromyalgia (FMS) is chronic pain in one's muscles, ligaments, and tendons, frequently accompanied by fatigue. FMS can weave in and out of one's life, or become a complex chronic debilitating condition that severely limits quality of life.

According to the Mayo Clinic, the almost constant, aching pain must be on both sides of the body and both above and below the waist for accurate diagnosis. Also, there are nine key tender points that feel additional pain that when pressure is applied (See Figure 3). Thus, hypersensitivity to touch can make the slightest touch a painful one.

The Mayo Clinic also states that people with FMS may also have co-existing conditions, including chronic fatigue syndrome, depression, endometriosis, irritable bowel syndrome, lupus, osteoarthritis, posttraumatic stress disorder, restless leg syndrome, and rheumatoid arthritis. Typically when the patient is exposed to periods of stress, FMS symptoms will flare up, or become heightened.

The cause of FMS is still unknown. Existing theories on the etiology of FMS are often misunderstood, or unrecognized. It is considered to be a rheumatic condition. Patients often describe FMS as arthritis of the fibrous tissues in their body.

Because the cause of FMS is not fully understood, treating this condition can be difficult. Most FMS patients cannot tolerate the side effects of many of the medications that are currently used for treatment. Some of the medications used are muscle relaxers, low doses of tricyclic antidepressants, and dual reuptake inhibitors (i.e. Cymbalta, Effexor, and Ultram). Some people with FMS who have had little success with other medications, will be treated with long-acting opioids, such as Methadone or extended-released Morphine. Many patients are treated with a combination of medications. The medications are often used to increase the patient's functioning abilities and quality of life, then are decreased with the reduction of symptoms. Two particular drugs have recently shown promise in the treatment of FMS: prebagalin (Lyrica) and gabapentin (Neurontin).

Universally, the most important treatment involves self-management techniques, such as relaxation and meditation, a good sleep regimen, a healthy diet, and exercise, as much as the body allows. Health educators play a key role in social support and education for patients living with fibromyalgia in helping them make the necessary health behavior changes, and consequently improving their quality of life.

For further information, visit the following websites:

Fibromyalgia Network: www.fmnetenews.com

National Institute of Arthritis and Musculoskeletal and Skin Diseases: www.niams.nih.gov/hi/topics/fibromyalgia/fibrofs.htm

National Fibromyalgia Association: www.fmaware.org

The American College of Rheumatology: www.rheumatology.org

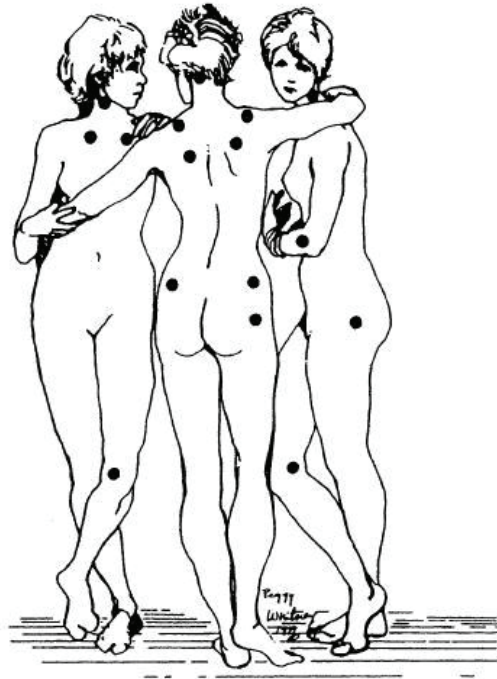


Figure 3. Tender point locations for the 1990 classification criteria for fibromyalgia (The Three Graces, after Baron Jean-Baptiste Regnault, 1793, Louvre Museum, Paris).

Taken from: Wolfe, F., Smythe, H. A., Yunus, M. B., Bennett, R. M., Bombardier, C., Goldenberg, D. L., Tugwell, P., Campbell, S. M., Abeles, M., Clark, P., et al (1990) The American College of Rheumatology 1990 Criteria for the Classification of Fibromyalgia. *Arthritis Rheum.* 33,160-72

Autism: The New Epidemic?

By Correspondent Hannah Bronsky

The Center for Disease Control and Prevention (CDC) calls the current increasing autism trend “an epidemic.” Data released by the CDC in 2007 shows that autism spectrum disorder (ASD) is diagnosed in one out of 150 eight-year-olds in selected areas in America. The CDC also states that it is still unclear how much of the trend is owed to more diagnoses (in terms of identification and classification), as opposed to a true, actual increase.

Fellow MPH Student Deborah Danielewicz is also the Mother of twin boys: One with a confirmed ASD diagnosis, and the other not officially diagnosed but likely to fall on the spectrum. While Danielewicz agrees with the CDC on one hand, she remains skeptical on the other. Danielewicz believes that an increase in publicity of the disorder and broader diagnoses criteria could be partially attributed to the rise in autism diagnoses.

What drives the extent of the increase in ASD cases is up for debate. Danielewicz feels that the skepticism behind the debate should steer ongoing research towards the causal factors of ASD. According to the CDC, a causal relationship between autism and thimerosal-containing vaccines, such as the ones for influenza and measles-mumps-rubella (MMR), is rejected.

Danielewicz agrees that a link doesn't seem likely. “However, any potential exposure that could increase the risk for autism needs to be studied,” she says, adding, “It is our job as public health professionals to be able to analyze and critically assess the current data so that we are informing the public with evidence-based education.”

More importantly, Danielewicz feels that as public health professionals, we must consider how education can impact communities, and how we can help people with disabilities become integrated in their communities. “[ASD] is a lifelong developmental delay and a complex condition. Everyday is a challenge,” says Danielewicz. “There are 52 million people living with disabilities in America. Whatever group you work with will have people with disabilities in their communities.” Danielewicz advises to always keep the subset of that population in the back of one's mind. “How are they being served? Even if you don't have the expertise, there are people who do, and who can help,” she prescribes.

The etiology of ASD leaves parents like our Danielewicz between a rock and a hard place. “I care what causes [ASD], but I also need to raise my child,” she says. “The general public doesn't know what autism is and it's very misunderstood. ASD children will become ASD adults. How are we going to ensure that they are integrated into our communities? How are we going to support their transition? We need to think long term because it's a long-term issue.” Public health professionals are in many ways advocates for people with health disparities; it is their job to close that gap.

“Autism spectrum disorder children will become ASD adults,” Danielewicz says. “How are we going to ensure that they are integrated into our communities?... We need to think long term because it's a long-term issue.”



Deborah Danielewicz's boys: Ethan (on left) and Aleksander (on right)
Photo courtesy of Deborah Danielwicz

If you're interested in being a part of The Harbinger Team, or have an interesting news tip or story, please contact Editor-in-Chief Maytal Bar-shir at TheHarbingerEditor@gmail.com. We hope you've enjoyed this publication and look forward to bringing you more in semesters to come!

*Sincerely,
The Harbinger Team*

