



July 2016

Dear Friends,

Like many single-disease organizations, in past years ACP organized large events—marathons, galas, a shoe ball—to increase awareness of our work and raise unrestricted funds. But with a staff of just 6 and a large roster of programs and initiatives to be developed and administered, we are grateful that throughout our history, a cadre of hard working, energetic and committed friends of ACP have independently organized events that generate significant funds to support our work. To call them our heroes and heroines is an understatement! In this issue, we profile 3 of them – Marion Leeds Carroll, Patrick Curley and Eliza Duddy -- and describe the ways they have managed to convert activities they enjoy – and might undertake anyway – into opportunities to raise much needed dollars. In the coming months, we will bring you additional stories of other ACP heroes. There are more than we can cover in just this one issue!

This month we also profile Elizabeth Jameson, an artist, former civil rights lawyer, social activist, mother and wife living in the San Francisco Bay Area. In the words of journalist, Shelby Hartman, Jameson has “chronicled her multiple sclerosis by making vibrant prints of her magnetic resonance imaging scans (MRIs) as she’s begun to lose function of her x`hands, feet, and voice. [Her work] illuminates the beauty and imperfection of the brain—the amorphous folds of tender tissue, the backbone reminiscent of pine needles shooting out from a rigid spine, and delicate strings of looping blood vessels—in bright reds, yellows, and aquamarines.”

These four people have been touched by MS. Each one is extraordinary in his or her own way. They are a diverse group. What they have in common is creativity, drive, energy and the belief that as individuals, we can make big, lasting impacts on our own life trajectories and on the lives of others. We think you will find their stories inspiring and thought-provoking.

Also inspiring is the latest news from the ACP Biorepository, which this month sent five requests to the committee that oversees distribution of samples to scientists. The requests come from scientists exploring a diverse set of research questions, all pertaining to MS.

The Power of Three: Singing, Rowing and Running for a Cure

By Katina Leodas

Singing for a Cure

Marion Leeds Carroll is an experienced opera singer, stage director, and website designer who resides in Arlington, Massachusetts. Since 2003 she has applied her talents and love of music to raising funds for ACP, a disease she has lived with since 1988. Every year on the last Sunday in October, Marion and a group of colleagues perform a concert at a local church, donating all proceeds to ACP. What began as a vocal-only “Sing to Cure MS” concert has grown into “Music to Cure MS,” featuring solo instruments and chamber-music ensembles as well as singers. In 2008, 2010, and again in 2016 (the 14th concert year!) Marion has received grants from the Arlington Cultural Council to offset the costs of organizing and publicizing the event.



Singer, Marion Leeds Carroll

Marion was introduced to opera at age 12 when an aunt gave her a recording of *The Mikado*, a work by the Victorian-era librettist and composer Gilbert and Sullivan, whose comic operettas are beloved across the English-speaking world. By the time she made it through Barnard College, which she claims to have chosen solely for its then-active Gilbert & Sullivan Society, Marion discovered Mozart, Verdi, Puccini, and a few other familiar operatic composers.... but she never lost her love of Gilbert & Sullivan. Post-college she was a founding member of the New York Gilbert and Sullivan Players, which first performed on a “Wenger Wagon,” a fold-out van that’s the stage equivalent of a murphy bed. She moved on to perform and direct Gilbert & Sullivan and other opera in New York and Massachusetts.



Marion & fellow singers

As her MS symptoms grew, Marion began limiting her performances, concentrating instead on directing and organizing concerts. The story of ACP’s founder, who recognized that he couldn’t cure MS himself but could use the skills he possessed to transform MS research, inspired her to use her own skills to support ACP by creating her annual Music to Cure MS concert.

These days, the 2-hour concerts are performed by a group of professional-level musicians (all friends of Marion) who perform a diverse repertoire of classical music in multiple languages, including English. But don’t be scared off; Marion always publishes a detailed program with translations of all pieces sung in foreign tongues and précis of the stories that are the subjects of the musical selections. Over the years, Marion’s concerts have generated an impressive \$30,000 for ACP. Says Marion, “I am pleased to be able to take a skill I possess, convert it into an activity I enjoy, and apply it to benefit something I believe in.”

The next Music to Cure MS concert will be held on October 30, 2:00-4:00 p.m. at the Park Avenue Congregational Church in Arlington, MA. Read more at www.singtocurems.org.

Rowing for a Cure

In addition to enjoying the music at Marion's concert in 2010, one member of the audience, **Patrick Curley**, was inspired to organize his own event to benefit ACP. A busy elder law attorney in Stoneham, Massachusetts who recently joined the ACP Board of Directors, Patrick is a strong and enthusiastic athlete, who had previously participated in charity runs. Similarly to Marion and Kemp Jaycox (whose walk in Banff National Park was described in last month's newsletter), Patrick was drawn to the idea of organizing an event of his own choosing, something he loves doing that would be challenging, would engage his friends and family and achieve something beyond the completion of the challenge -- fundraising for ACP.



An experienced rower from his days as an undergraduate at Dartmouth College, in 2014 Patrick entered a race that takes place on the Essex River in Ipswich, Massachusetts every year, and asked friends and family to sponsor his participation. In his appeal, he described ACP in detail and, as one would expect from a good lawyer, made the case for supporting it. Meanwhile, ACP staff-member, Lindsey Santiago, created a separate webpage for his event to facilitate contributing online.

Patrick preparing to row the Essex River race

Rowing a scull (a single rowing shell) on this beautiful and ever-changing tidal river, Patrick completed the five-mile race and netted an impressive \$3,000. Hard as it was, the experience whetted his appetite for more. This past February, Patrick piggybacked an independent fundraiser on another well-organized annual rowing event, the World Championship of Indoor Rowing, held in Boston. The grueling competition, in which approximately 2,500 people from over 30 countries endure what Patrick calls “roughly seven minutes of pure pain, pulling 2,000 meters on an ergonomic rowing machine,” was a challenge for even this seasoned, disciplined athlete. He says, “Prior to 2016, I had last competed in the World Indoor Championship in the spring of my freshman year at Dartmouth, when I was just 18 and in the best shape of my life! Needless to say, my 43 year-old body did not respond quite the same way as it did in 1991. But I trained really hard, competing in the lightweight (less than 165 lbs) veterans (ages 40-49) men's division.” The race saw five world records set, including one by a 95-year-old man! Patrick, his friends and family raised just over \$5,000.

Combined, Patrick's 2 fundraisers have netted \$8,400 for ACP. Of his decision to support ACP, Patrick says, "I have been a long-term donor to ACP because I have a legal practice of senior citizens and people with long-term physical disabilities, including many with MS. I feel very fortunate to participate in these tough athletic events because I know many with MS cannot." Patrick says he's looking forward to doing another independent fundraiser for ACP in 2017 (event and date to be arranged) and he characterizes the work of organizing it as "no sweat off my back." He says, "I composed and distributed a short email/letter to friends and family, including people I know from Dartmouth and other places, asking them to



Patrick training with his most enthusiastic fans, his children Alan & Hannah

support my participation and educating them about ACP and the important work it does. Many of my contacts then forwarded the invitation to others in their networks and posted notices of the event on their Facebook page. In this way, with a relatively modest-sized community of friends, I was able to tap into a community of passion. Sometimes, people with passion have compassion."

Running for a Cure

Eliza Duddy is a fitness enthusiast whose love of running was nurtured by her mother, Alice. After Alice was diagnosed with MS, Eliza began running benefit races for ACP and the National MS Society and in 2014, she decided to organize one herself to benefit ACP. At the time, she was working at The Fieldhouse, a sports complex in Sudbury, MA where she found herself surrounded by people who shared her passion for fitness. Working through her community of friends and fellow runners, Eliza recruited over a hundred runners, aged 3 and up, to run several races of varying lengths and challenge levels.



Eliza with her parents Alice and Paul

A bundle of positive energy, Eliza had run charity races before, but had no experience organizing one. Nonetheless, she threw herself into the project, securing approval from her local Board of Selectmen; negotiating and planning the race routes with local police; publicizing it through email, a notice in the *Town Crier* and flyers she composed and posted on bulletin boards around the community; gathering sponsorships from more than three dozen local businesses; engineering the logistics of race registration and timing; and, securing signage and T-shirts.

On a cool November day in 2014, 139 registrants gathered at the starting line to run one of 2 courses: a 5K for adults and a ¼ mile “Fun Run” for kids. The event was hugely successful, netting just over \$3,000, the bulk of it through sponsorships and raffles of goods and services donated by local companies. A novice fundraiser, Eliza likens the experience of asking people for money that first year to ripping off a Band-Aid. “It’s scary and hard the first few times, but gets easier with practice until it ceases to be painful.” And, she was surprised at the number of business owners she approached who turned out to have a personal connection to MS and so were especially receptive to her solicitation.

The success of Eliza’s first race made for shorter work securing runners, volunteers and sponsors of the second race in November, 2015. That year, 159 people registered for three races: 5k, 5 mile or kids’ fun run. Dozens of local sponsors (including every single company that had given in 2014) received placement of their company’s names and logos on the runners’ T-shirts, the mile markers and the finish line, enabling Eliza to contribute over \$6,000 to ACP.



Today, as she contemplates organizing her next race—tentatively a Thanksgiving Day “Turkey Trot” – Eliza sounds like an old hand. “Once I begin publicizing them, the races have a way of generating momentum and enthusiasm all by themselves. So many people I’ve met in the course of organizing them have a personal connection to MS. And whether they have MS themselves, or know someone who does, people are inspired by an activity that’s being done for good, and not to make a profit.”

Eliza kicking off the kid’s fun run!

Recently, Eliza began working as a Production Coordinator for MKTG, a lifestyle marketing company that supports the production of participatory athletic events. In her new job, she helps Nike produce free running-related gatherings that generate brand loyalty. It’s no accident that she landed the job. “The fact that I had independently organized successful charity runs played a big role in my being considered for this new job,” says Eliza. “I am MKTG’s sole employee in Boston, so it was important for me to demonstrate that I could get things done, working independently and with little supervision. My experience organizing the fundraisers for ACP were the examples I cited.” Other than starting a new job, Eliza still runs competitively. In May, she joined an international crowd of more than 9,000 to run the Copenhagen Marathon, a 42 kilometer “charity race” through the streets of Copenhagen, Denmark, accompanied by bands and dancers that make the event look as much like a samba festival as a marathon. And true to form, Eliza raised money while having fun and building awareness. She secured \$8,000 in contributions for SMILE Mass (a charitable organization that works with families raising children with disabilities) and pushed Victoria Conrad, a 25-year old family friend who has cerebral palsy.

If you or someone you know is interested in organizing an independent fundraising event to support ACP, please contact Lindsey Santiago at lsantiago@acceleratedcure.org or 781-487-0013.

Elizabeth Jameson's Beautiful Brain

By Katina Leodas

Elizabeth Jameson is a 65-year old visual artist based in the San Francisco Bay Area who uses imaging of her own brain to create a new kind of self-portrait. Throughout the course of her disease, Elizabeth has spent countless hours in the cramped darkness of the scanning machine; her brain has been the subject of innumerable magnetic resonance imaging scans (MRIs). She identified MRIs as one of the major symbols of MS, and sought to incorporate the images into her art practice because she wanted to take unsettling and frightening images and transform them into something that would invite individuals to look directly at the imperfect brain with curiosity and fascination. As a printmaker, she produces large, vivid, and colorful etchings that at first glance appear abstract but in fact are literal representations of the inside of her brain. There is no shortage of imagery to work with.



Artist, Elizabeth Jameson

The artwork, which has been widely praised and displayed around the globe, is vibrant and moving in ways that challenge conventional expectations of the artist, who is constantly adjusting to her illness. She continues to create, despite the fact that she is now a quadriplegic, using a wheelchair to navigate her environment and collaborating with others to continue exploring new mediums.

Prior to her diagnosis with MS, making art was pretty far from Elizabeth's mind. Sure, she had doodled with pencils and drawn pictures with her kids. But as an adult, she had never picked up a paintbrush. For 15 years Elizabeth was a civil rights and healthcare lawyer who represented vulnerable populations (including incarcerated children) in their efforts to gain access to medically necessary healthcare. The work took her in and out of prisons and healthcare facilities, across the country. It eventually led her to be invited to consult with the White House on the healthcare reform efforts of the 1980's, and contributed to the creation of new law defining healthcare entitlements for juveniles. These important reforms are still advanced today through the Affordable Care Act. Her growing interest in the field led Elizabeth to complete a post doctorate fellowship in healthcare policy at the medical school of the University of California, San Francisco (UCSF).

Then one day in the late 1980's while playing with her two young sons on the playground, Elizabeth suddenly lost the ability to speak. After numerous MRI procedures that revealed the existence of a large lesion on her brain, she underwent brain surgery at UCSF. This was followed by a diagnosis of progressive MS and a full year of physical and speech therapy, during which she regained the ability to walk with a cane and to speak English, although with a distinctly (and uncontrollably) Swedish accent!

After her recovery from aphasia, Elizabeth was no longer comfortable practicing law in a courtroom. A friend recommended she consider visual art as an alternative means of communication and encouraged her to register for a class at a local community arts center. That first course led to others and eventually Elizabeth enrolled at California College of Art in Oakland, California. The program instilled confidence in her newfound artistic capabilities and instincts and exposed her to multiple disciplines and materials. She began by painting flowers and human portraits on silk, but soon migrated to printmaking and a kind of "portraiture" that is rooted in the experience of people with what Elizabeth calls "imperfect brains."



“In 2008, when I began this work, people with MS weren’t routinely given the actual films of their MRIs,” says Elizabeth. “Instead you received a plastic hard copy of a scary image in black and white. I wanted to find a way to de-mystify MRIs, to make them accessible, less scary. I used a process called solarplating to transfer my MRI images from the transparent film onto copper aluminum plates (with chemicals activated by the heat of the sun), and then used the copper plates to print the images on paper. Afterwards, I added color with paints, colored pencils, and chalk pastels.”

Celebration, Solar Etching, 2010 (angiogram of Mark's brain)

The etchings, which reside in institutions, galleries and universities around the world, are far removed from black-and-white MRI scans, and capture in vivid colors the anatomical details of the brain—veins, folds, spinal column, even the lesions caused by MS. They have drawn the attention of neuroscientists at Harvard University, UC Berkeley, Yale University, and King’s College in London, among others.

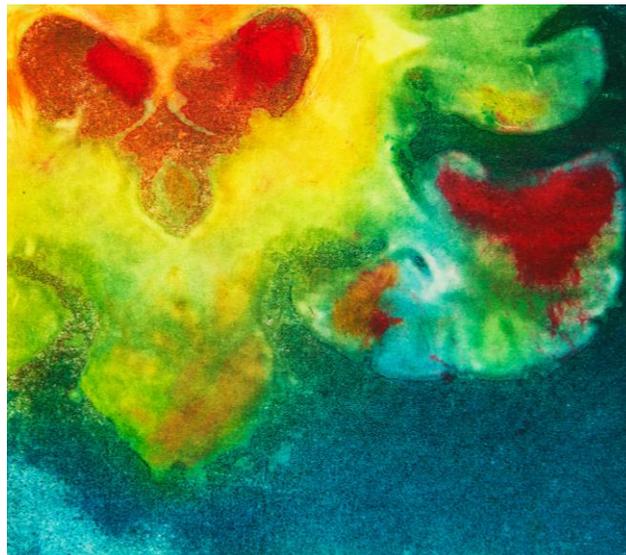
In describing her purpose, Elizabeth has written, “My goal is to make it possible to stare at images of the brain and not be afraid, to find beauty in it without ignoring the complexity of the disease that is attacking it. Medical technology generates MRI images that bunch black and grey pixels into a prognosis collected in hollow, windowless rooms. In office visits, we tend to be defined by the technology. We talk to the image rather than talking about the disease. Yet the brain is the locus of personality, of identity, of self. I use art to expose the beauty and intrigue of parts of the brain in a way that people do not normally see in exam rooms or laboratories. I invite viewers to consider these images of the brain in a light that includes personality and uniqueness, one that bluntly denies the sense of being invaded by the medical technology that can make patients feel isolated and disconnected from their bodies, and their unique sense of self.”

This year, Elizabeth used a 7T MRI image—created using one of the most powerful MRI imaging techniques—to create an etching of a prominent neurologist’s brain. The image reveals some of the most detailed views of the architecture of the brain—amongst the most detailed views available yet in science. Elizabeth’s piece, which measures 16’x4’, is currently on display in the lobby of UC Berkeley’s Li Ka Shing Center for Biomedical and Health Services.

Elizabeth’s artwork has captured the attention of people who live with brain illnesses. This has led to an increased interest in using art for social engagement with the MS community as well as the larger community of people living with disease and the health providers who care for them. She recently created a website, www.facingms.org, which contains photographic portraits and short bios as well as six individual narratives of participants' experiences living with MS.

Currently, she is collaborating with healthcare professionals on artwork that would build community among those who treat and suffer from illness. She is hoping to take the portraits and narratives of FacingMS to the healthcare settings where patients and visitors can add to the project by recording their own narratives in kiosks outfitted with the necessary equipment.

Elizabeth says, “As someone with a degenerative disease who has spent countless hours in waiting rooms, I am familiar with the feelings of loneliness and isolation, despite being surrounded by people. There is such untapped potential for building community within the healthcare setting. I want to connect people going through the very experiences that inspired my artwork and to create a reverent space for contemplating the beauty and architecture of the brain.”



Valentine, Solar Etching, 2010 (coronal view of the brain stem, cerebellum, and lateral ventricles)

For much more information about Elizabeth Jameson and her artwork, please visit www.jamesonfineart.com.

Latest News from the Biorepository

This month we sent five additional Repository sample requests to our oversight committee for review and approval. These planned studies, from corporate and academic sources, include a test of epigenetically modified DNA as a diagnostic for MS, a follow-up study to confirm a mutation associated with transverse myelitis, a study to seek correlations between genotypes and environmental factors and MS disease characteristics, a microbiome-immune response MS study and a “quality control” analysis of some neuromyelitis optica samples.

If you would like more information about research being conducted with Repository samples and data, please contact David Gwynne, ACP’s Director of Alliances and Collaborations, at dgwynne@acceleratedcure.org.

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