September 2016

Dear Friends,

Somehow September always signals “back to school” even if it’s been years since we, or our children, were actually lacing up new shoes and heading into classrooms.

September means a quickening of the pace and that’s been true here at ACP: ACP staff members spend an exciting week in London at ECTRIMS, the world’s largest conference focused on MS (stay tuned for more about what they heard and saw in next month’s issue); REAL MS™ is well into into its first month of data collection from the iConquerMS™ participants (read the press release here); we submitted an initial proposal to PCORI for research and engagement funding; and, the Repository continues to receive requests for samples from research labs far and near.

This month we profile, Thomas Aune, a Nashville MS researcher who is using samples from our Repository to develop a blood-based method of diagnosing MS that is an alternative to the use of MRIs. It promises to be faster, less expensive and less invasive, as well as a route to early detection.

We also take a moment to give credit where credit is due, by introducing you to three of our longest serving board members. Linda Kanner, David Blohm and Bruce Sachs have given a combined 37 years of service to ACP. Without their smarts, energy, commitment and keenly analytic minds, we would not be where we are today. You will “meet” the rest of our board in the coming months.

ACP’s Repository Speeds Research, Cuts Costs, and Leads to Diagnostic Breakthrough

Tom Aune is a professor of medicine at Vanderbilt University in Nashville, as well as an MS researcher and entrepreneur. He is also an enthusiastic proponent of using samples and data from the ACP Repository to quickly advance MS research. Says Tom, “I have used the ACP Repository samples extensively and I calculate that it has saved me close to 5 years and over $1.5 million. Another way to think of it is that an experiment that has cost me $20,000 to do with samples from ACP, would have cost me $1 million with samples obtained from other sources. The value, and the positive impact the

repository has had on our research and on the lives of some people with MS, really cannot be overstated!"

Since 2005, Tom and a team of colleagues have been searching for a means of diagnosing MS with a simple blood test. They hope to find an addition to the use of magnetic resonance images (MRIs), which are costly, invasive and slow, because patients typically undergo multiple MRIs of different parts of the brain over a period of months or even years to determine whether brain degeneration has occurred. It is not uncommon for the process of diagnosing MS to take five years from the date that symptoms were first reported.

But early intervention with one of the available disease modifying therapies may lead to better outcomes. In contrast, delayed or slow diagnosis can result in unnecessary damage to the brain, a threat that was underscored by the widely praised report: Brain Health: Time Matters in Multiple Sclerosis. Published in 2015, the report recommended specific actions to achieve the best possible outcome for every person with MS. It stated, "Early intervention is vital" but noted that instead, "Significant delays often occur before a person with symptoms suggestive of MS sees a neurologist for diagnosis and treatment. This is despite diagnosis being 10 times more rapid now than in the 1980s and substantial evidence that early treatment is more effective than later treatment." The report urged healthcare professionals to "involve people with MS proactively in decision-making and in managing their disease," and referred to the need for "specialized diagnostic procedures."

Brain degeneration is not the only indicator of MS. Inflammation occurs when the body's own immune cells attack the nervous system, as can happen in people with MS along any area of the brain, optic nerve, and spinal cord. Tom's research led him and his colleague, Chase Spurlock, also a Vanderbilt faculty member, to establish a private biotech company, IQuity, which is focused on this indicator and has developed a gene expression test that can measure the inflammatory component and reveal the presence of MS at a point before it would be obvious from an MRI scan.

IQuity's new test analyzes ribonucleic acid (RNA) markers in a simple blood sample. Gene expression gives rise to a class of messenger molecule, called messenger RNA (mRNA) and changes in gene expression patterns are a "fingerprint" of disease. Measuring RNA molecules determines if the expression of the gene encoding that RNA is turned on or off. These measurements are captured through a simple blood test and provide a snapshot of information being processed in a living cell. Tom's research revealed that people suffering from MS exhibit a distinct RNA expression pattern in their blood. This is critical to early disease detection since those unique patterns distinguish them from patients with other neurological diseases. The test he and his colleagues have developed can identify these patterns and confirm a suspected diagnosis with greater than 90% accuracy.

Having access to the ACP Repository has enabled Aune and his colleagues to examine samples from people before a diagnosis of MS was delivered, at the point of diagnosis and following diagnosis, and to spot variations in messenger RNA patterns in each group.

Introducing the ACP Board of Directors

A board of directors is a body of elected or appointed members who, together with the CEO, oversee the activities of an organization. An effective decision-making board can strengthen a nonprofit organization in many different ways. It can oversee strategy and tactics, perform some of the tasks of the organization, support the organization's work in its community, bring necessary resources for better performance, advise the organization on financial, legal or other matters and help with fund raising. Today, the nonprofits that survive and thrive are the ones whose boards (and CEOs) are highly strategic and effective in identifying opportunities to pursue their missions.

At ACP, we are blessed with a board that matches these ideals, and then some. In the words of one of its members, Susan Friedman, "This is a board whose ideas and opinions make a huge difference to ACP, beyond the standard board activity of raising money." It is a diverse group of 8 generous people with different educational backgrounds and areas of expertise, each of whom cares deeply about accelerating MS research. Together, they form the backbone of our organization, without which we literally could not stand strong and tall. We thought you might like to "meet" them and so, in the coming months we will be introducing them to you, one-, two- or three-at-a time.

Linda Kanner, David Blohm and Bruce Sachs have served a combined total of 37 years on the ACP Board of Directors. All three were recruited by our founder in the very early years of our existence and all three have a very close personal connection to MS.

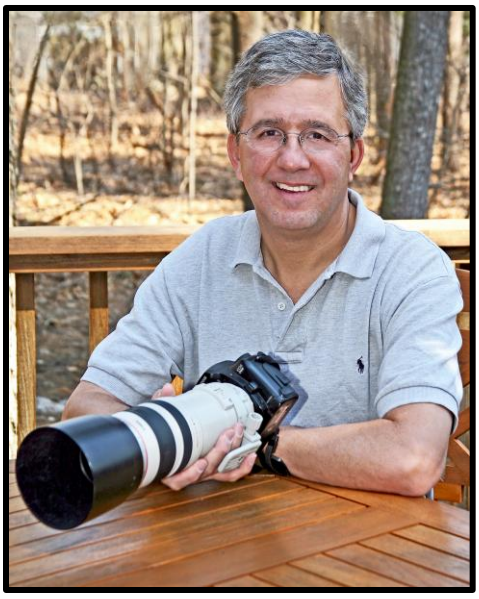
Our current Board Chair, **Linda Kanner**, is a retired corporate CEO, mentor to early-stage entrepreneurs, and experienced nonprofit board member who was introduced to ACP in 2008, a few months after being diagnosed with MS at the age of 63. Linda was not unfamiliar with the disease. In fact, she grew up watching an uncle become wheelchair-bound in his early 20's, at a time when treatments for MS had not yet been discovered. "Multiple Sclerosis," she says, "was the defining disease in my family."

Soon after learning about ACP, Linda joined the board and began applying her considerable skills, creativity and optimism to the growth of the organization. Her career in business includes 25 years managing business units in diverse large corporate settings (from industrial products to consumer banking to retail footwear), with a focus on new products and new businesses. She subsequently worked 5-6 years in the start-up world, where she was either CEO or COO of several venture-funded businesses.

In the non-profit arena, Linda's experience is equally relevant. She has been a trustee of Beth Israel Hospital; an overseer and member of the Research Advisory Board to the Beth Israel Deaconess Medical Center; a founding board member, now overseer, of the Huntington Theatre Company; and, a director of the Commonwealth Institute. She remains an active "change agent," interested in shepherding "newness" into established organizations as environments and technologies provide

opportunities. It is ACP's orientation to changing old paradigms of research by utilizing technology that continues to excite her.

Educated at Cornell (BA), Simmons (MSW) and Harvard (MBA), Linda is mother to 3, grandmother to 4 and wife to a physician.



David Blohm is a retired software entrepreneur with over 30 years' experience launching and building successful companies. He co-founded MathSoft, Inc. in 1985, a firm that developed and marketed mathematical calculation software sold to engineers, scientists, teachers and students. Under his leadership it grew into a multi-million dollar global firm with 205 employees and offices in Seattle, London and Japan. The company went public in 1993 and was acquired by Parametric Technologies in 2006. Over a million copies of MathSoft's flagship product, MathCAD, have been sold. David's interest in educational software caused him to join SmarterKids.Com, a CD-ROM publisher of innovative children's educational software. He led the company as CEO and transitioned it to an award-winning Internet retailer of children's educational products and services. David guided that company through its initial public offering and subsequent merger in 2001.

At about this same time, David was diagnosed with MS and, soon thereafter, he met the founder of ACP. Inspired by the organization's strategy to advance scientific research towards a cure, he joined the board the following year and he has remained a member since 2002. David's past non-profit and public service activities include numerous leadership roles. He served as Chairman of the Massachusetts Software Council and its educational foundation; a Trustee of the Boston Children's Museum; President of Congregation B'nai Torah in Sudbury; a member of Massachusetts Governor Paul Cellucci's Economic Development Council; an overseer of the Boston Science Museum; and, a member of the WGBH Corporate Executive Council. He is currently a board member of the Fells Historic Estate and Zoning Board of Appeals for Newbury, NH.

David is a graduate of Boston College. Today he is an award-winning nature photographer (work can be seen here) who lives near Lake Sunapee in New Hampshire. He and his wife Mary have four children and three grandchildren.

Bruce Sachs first heard about Accelerated Cure Project in a 2001 meeting with the organization's founder. He immediately recognized it as "a novel and powerful" way to accelerate research towards a cure for MS, and soon thereafter wrote a check that helped the organization launch. Bruce is not a guy who's easily impressed, either. Trained as an engineer, CEO of two public companies, and partner in venture capital firm CRV (formerly Charles River Ventures) since 1999, his expertise is selecting the really good ideas from among the horde.

Educated at Bucknell (BS), Cornell (ME) and Northeastern (MBA), Bruce began his professional life at AT&T Bell Labs. After helping to grow a start-up, he joined Xylogics, an early Internet hardware pioneer, eventually becoming CEO and leading the company through its acquisition by Bay Networks. This was followed by similar success at Stratus Computer prior to his joining CRV. As an investor, Bruce has played an active role in the start-up and growth of dozens of companies, the bulk of them in the areas of Enterprise and Service Provider Infrastructure; Cloud; Robotics; and, Consumer Electronics.

Bruce cares about curing MS. His wife Kim was diagnosed with the disease soon after they wed 30 years ago. He is an admirer of the Open Source Movement — the collaboration and free sharing of intellectual output among software engineers that led to the creation of Linux and other game-changing programs. He believes that ACP's model, which inspires similar behavior among MS researchers, can accelerate the search for a cure.