

Vol. 8, No. 2 | A publication of the Massachusetts Biotechnology Council | Spring 2015

MassBionews

MASSACHUSETTS BIOTECHNOLOGY COUNCIL

YEARS OF INNOVATION

2015



OPPORTUNITIES EMERGE BETWEEN LIFE SCIENCES AND INFORMATICS

MassBio, the Mass Technology Leadership Council (MassTLC) and leaders from life sciences, technology innovation, academics, venture capital and government gathered on May 13 to explore the challenges and emerging opportunities in life sciences information technology and informatics (LSIX) in the region.

The event, Life Sciences Informatics: The Massachusetts Opportunity for Global Leadership, was held at the Microsoft New England Research and Development Center. It explored the market opportunities at the intersection of life sciences and

technology and how life sciences companies and healthcare organizations across Massachusetts are collecting data—from genome sequences to drug screens, clinical trial data, electronic medical records, claims data and even patient-reported data.

"If we can utilize our partners in technology, that will only make us more dominant in research and development," said MassBio President & CEO Robert K. Coughlin. "Time is precious. Any opportunity to work together as industries to do our job better will benefit patients."

"As we look at technology, it's not one thing," said MassTLC

President & CEO Tom Hopcroft. "It's security, mobile communications, robotics—many things. We want to use that technology to help solve real problems and help people live longer and healthier lives."

R.T. (Terry) Hisey, Life Sciences Senior Strategy Principal of Deloitte Consulting, delivered the conference keynote, highlighting strategic ways in which companies are leveraging informatics and becoming insight-driven organizations.

See INFORMATICS Page 7

REFLECTING ON 30 YEARS AS THE INDUSTRY'S VOICE



ROBERT K. COUGHLIN

As we recognize MassBio's 30th anniversary as a trade association—and the world's very first biotech trade association at that—I'd like to take this opportunity to thank you all for your continued support over the years and to celebrate how far we've come.

Looking back at 1985, a new industry was emerging called genetic engineering and leaders thought a trade organization to represent the collective voice might help guide policymakers in developing regulations. Today, Massachusetts is the world leader in the life sciences. It is a great achievement to have accomplished so much in 30

years, but we must continue to take a leadership role in articulating the value of our industry—to the economy, to the healthcare system and, most importantly, to patients around the world.

We have had a busy spring, and hope all of you who attended our signature events-the 2015 Annual Meeting and the first ever Life Sciences Informatics Conference—enjoyed the panels, speakers and networking opportunities. At our Annual Meeting, we continued critical conversations on defining value in healthcare and innovative early-stage funding models. At the LSIX Conference, we discussed the life sciences

informatics funding environment, emerging opportunities and innovative partnerships.

Coming up, I encourage you all to attend the 2015 BIO International Convention in Philadelphia, as well as BioPharm America, right back here in Boston.

We look forward to working with you throughout the remainder of this very special year. I cannot wait to see what the next 30 years will

Robert K. Coughlin is President & CEO of MassBio.



A PUBLICATION OF: **Massachusetts Biotechnology Council**

> 300 Technology Square Cambridge, MA 02139

617-674-5100 **www.massbio.org**

Robert K. Coughlin President & CEO

Joseph Fazio VP of Finance & Administration

> Iohn Hallinan Chief Business Officer

Sarah MacDonald **Executive Vice President**

Kendalle Burlin O'Connell VP of Member Services

BOARD OF DIRECTORS

Glenn Batchelder, Chair Abbie Celniker, Vice Chair Michael W. O'Hara, Treasurer David Lucchino, Clerk Geoff MacKay, Immediate Past Chair Caren Arnstein Mark R. Bamforth lim Burns Tim Clackson

Renee Connolly Geoffrey Cox Jeffrey Elton Chris Garabedian Scott Gillis Steven P. Gilman Robert Gottlieb Sam Guhan Jose-Carlos Gutierrez-Ramos

James Hoyes Edwin Kania Laurie Bartlett Keating Melissa Bradford Klug Mark Leuchtenberger

Liz Lewis Antony Loebel William McDermott

Lisa Olsen John Orloff Paris Panayiotopoulos Michael Pellini Adelene Perkins

Deanna Petersen Alice Pomponio Steven Richter Rick Russell Amit Sachdev

Kathleen Tregoning Charles Wilson Lawrence Wittenberg

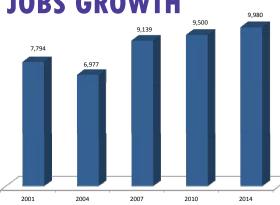
PRODUCED BY:

GRANT COMMUNICATIONS CONSULTING GROUP

> Boston/New York 781-598-8200

gccg@grantgroup.com www.grantgroup.com

MASSACHUSETTS BIOMANUFACTURING **JOBS GROWTH**



Source: Bureau of Labor Statistics, QCEW (NAICS 3254)

Biomanufacturing is a key competitive differentiator within the life sciences and a major job growth and economic development opportunity for Massachusetts.

To open the biomanufacturing dialogue among key stakeholders, MassBio has launched new programming and will convene industry leaders with Jay Ash, the Commonwealth's Secretary of Housing & Economic Development, for a Forum on June 5. Visit www.MassBio.org to learn more and register.

BIOTECHNOLOGY & COMPLIANCE

Training the Workforce for Biotechnology & Compliance

32 students graduating May 30th with the knowledge to enter the biotechnology workforce right away!

Biomanufacturing Job Fair June 25th 4:30-7:00 **Come Meet Our Students!**

State-of-the-art incumbent worker training on the AKTA pure system with **UNICORN** software

Students Available for Internships!



- GMP/cGMP training
- Documentation (SOPs, Batch Records) **DNA** techniques (PCR, Gene Transfer)
- Tissue Culture (cell viability & scale up)
- Cell Growth in Spinner Flasks
- **Wave Rockers**
- Bioreactors (single-use & traditional) Sterile Welding
- SciLog Filtration systems, TFF, UF/DF
- Quality control (bioburden, endotoxin, pH, conductivity, non-viable particle tests)
- Column packing
- Tissue/Aseptic Techniques
- Liquid Chromatography (HPLC) & Gas

Bruce Van Dyke, M.S., Chair, Biotechnology and Compliance 617-984-1669 | BVanDyke@quincycollege.edu Quincy College | Saville Hall | 24 Saville Ave, Quincy, MA 02169

NEW MASSBIO MEMBERS

Abpro Adaptive Insights Alliance Pharma Astrocyte Pharmaeuticals Baxter BBK Worldwide Biogate Technologies BioMotiv **Brown University** Catalent Pharma Solutions Chiasma Pharma Collegium Pharma CoLucid Pharmaceuticals Cote Pharma Covance Crispr Therapeutics Curadel CuriRx DLA Piper Dovel Zapthink EDC Western Mass Framingham State University Hybrigenics Corp Invest Northern Ireland Keryx LabMinds MacDougall Biomedical Communications Minerva Bio MyoSyntax New England Discovery Partners Paratek Pharmaceuticals PharmaLex

Planet Pharma **PNA Innovations** Pro-Cure Health Designs qPharmetra Rubius Therapeutics Science/AAAS SciSafe Semma Therapeutics Summit Therapeutics TocopheRx

Vacuubrand Vericel WuXi AppTec Sales



Q&A with NAN DOYLE AND JOHN TAGLIAMONTE

MassCONNECT MENTORS



Nan Doyle is Director of Strategic Partnerships & Development in the Department of Pathology at Massachusetts General Hospital.

What have you learned in your role as an advisor?

The importance of a balanced mentor team, both in expertise that is relevant for the startup and in willingness to commit time to the program.

MassCONNECT, MassBio's mentoring program, matches budding entrepreneurs with industry experts for in-depth, industry-specific support and mentoring. MassBio greatly appreciates the commitment of MassCONNECT mentors who graciously volunteer their time and considerable expertise to helping the next generation of entrepreneurs. For this edition's Q&A, we asked two long-serving mentors to share their advice and experience with us.

What's your favorite part of being a MassCONNECT mentor?

Seeing startups evolve as the weeks go by: the final showcase pitches are usually much more crisp, focused, confident and compelling.

Even more "favorite" is seeing the startup then attract interest and funding from investors, business plan competitions, SBIR's, etc. I also enjoy the connectivity and interaction with other mentors and with the investment community. We all learn from each other.

What is one piece of advice you'd like to share with budding entrepreneurs?

Focus on your audience — who are they, what do they care (or not care) about, how will your company solve a problem for them. Tell the

story as a problem in search of [your] solution, not the other way around!

What's your favorite part of being a MassCONNECT mentor?

I truly appreciate the innovation arising from first time entrepreneurs, spurred by their burning desire to serve patients in need. If my

experience can help advance a single product idea one step closer to better treating a patient, then my time has been well invested.

What is one piece of advice you'd like to share with budding entrepreneurs?

Interesting technologies in search of a market tend to be less successful. Having mentored many companies through MassCONNECT, the

successful entrepreneurs are those who listen well and can incorporate input from their mentor team while channeling their own and the team's resources into a comprehensive business story. Identifying the unmet need, providing a competitively advantageous solution, and mapping this onto a business plan with funding requirements has been a common theme of the many successful MassCONNECT graduates.



John Tagliamonte is Chief Business Officer at Oxyrane.

What have you learned in your role as an advisor?

Genius is not in a single person nor an entrepreneur's own knowledge and talents. Genius is serendipity that visits upon someone prepared to take a risk and who can inspire others

to follow a coherent path to address a medical need. Fellow mentors across all functions: R&D, law, finance, manufacturing, commercial, etc. have taught me a great deal about how to get a product or service from idea to serving patients.

CYCLE II

Technology Showcase
July 8

Mentoring meetings
July 11 to Sept. 9

Final Tech Showcase Sept. 10 Technology Showcase Oct. 20 CYCLE III

Mentoring meetings Oct. 26 to Dec. 17 Final Tech Showcase & Holiday Party Dec. 18

Applications are being accepted for future MassCONNECT cycles. The deadline for Cycle II is June 5 and the deadline for Cycle III is Sept. 18. For more information, contact John Hallinan or Rakhshita Dhar at 617-674-5100 john.hallinan@massbio.org or rakhshita.dhar@massbio.org.







4 — MassBio News SPRING 2015 MassBio News SPRING 2015 — 5



ANNUAL **MEETING** The Business of Science

VALUE ADDED

Annual Meeting fuels discussion on innovation and efficiency in bringing products to patients

Closing out MassBio's 2015 Annual Meeting, economist Andrew Lo—a professor at MIT's Sloan School of Management and one of TIME Magazine's most influential people—presented attendees with a possible solution to one of our biggest challenges: curing cancer.

"We have some of the world's most advanced healthcare centers within walking distance, as well as the world's best academic centers and the world's most vibrant biotech community," said Lo. "But we also have one of the world's largest asset management centers. We ought to bring that element into the discussion."

Lo said that while many investors are currently putting their money in "lower hanging fruit," they should collectively be looking at the bigger picture. He shared his vision of Massachusetts curing cancer through a creative megafund, advised by a board of scientific and business experts. If even eight percent of the state's population invested \$3,000 of their 401K in the fund, that would equal \$30 billion to be invested in a multitude of cancer

"Out of 150 investments, there's a 99.95 percent chance that at least one will succeed," said Lo. "You're almost assured a guaranteed success. Diversification changes the risk of

More than 400 biotechnology industry leaders gathered for the Annual Meeting, held at the Royal Sonesta Hotel in Cambridge. It took place over two days, March 26-27, and included discussions on precision medicine, defining value, reimbursement and market access, innovative ways to fund early-stage companies and more.

The event's opening keynote speaker, Kathy Guisti, Founder and Executive Chairman of the Multiple Myeloma

Research Foundation, shared

her vision of a world where

disease, even as that disease

evolves and changes.

patients better understand their

"As a patient myself, I knew

my genomics early on," said

Guisti, who was diagnosed

with multiple myeloma in

where every patient knows

mutation. With myeloma,

there's a constant need for

innovation because of the high

it's important to understand the

genomics of our disease. I've

often found myself acting like

a concierge, guiding people to

the right questions and

experts."

risk of relapse, which is why

their risk, subtype and

1996. "I'd like to see a world



MassBio Board Chairman Glenn Batchelder addressed the crowd.



Sarah Emond, Christopher Hansen, William Sibold and Glenn Batchelder participated in a discussion on defining value.

Since establishing the Multiple Myeloma Research Foundation in 1998, seven new drugs have been approved, nearly 30 treatments are in clinical trials and the life expectancy for patients has tripled. The foundation's CoMMpass Study is helping researchers gain access to each patient's genetic analysis and learn how patients respond to therapies, and the resulting data is placed on a public portal. Guisti said the more information patients give, the more their specific journeys can be mapped out for them.

"To truly bring value to patients, speed and efficiency are critical parts of the equation," said Guisti. "Every patient gets up and puts their feet on the ground for one reason—the hope that there will be a cure in their lifetime. I have been given so much time. I'm standing here today because of companies that believed in drug development. Know the importance of what you're doing and how much we appreciate it. If I'm this grateful, multiply that by hundreds of thousands."

During a conference-wide session on precision medicine, panelist Susan Hager, Vice President of Communications and Government Affairs of Foundation Medicine, followed up on Guisti's vision of strengthening communication and information sharing to advance research and drug development.

"If we look at cancer not as a disease of the body part but as a disease of the genome, we'll be able to match the right person with the right treatment at the right time, based on their genomic profile," said Hager. "As a patient, you don't have months and months to get educated. It's overwhelming. When patients come to us, we hope to empower them with a comprehensive profile to truly understand their genetic drivers."

The panel also included David Altshuler, Executive Vice President of Global Research and Chief Scientific Officer of Vertex Pharmaceuticals; Walter Carney, Chief Scientific Officer and General Manager of Nuclea Diagnostics; and moderator Jeff Elton, Managing Director of Life Science at Accenture.

"Advocacy is so important," said Carney. "We need to educate the population more about what's available to them. Not all diagnostics are created equal and we as consumers need to be getting the right information."

During a panel on defining value, Sarah Emond, Chief Operating Officer of the Institute for Clinical and Economic Review, defined the value of a product in two ways: (1) is it affordable, and (2) does it work?

"If manufacturers have dialogue with patients and insurers up front, they can better work within their expectations," said Emond.

Other panelists included Christopher Hansen, President of the American Cancer Society Cancer Action Network, Inc., and William Sibold, Senior Vice President and Head of Multiple Sclerosis at Genzyme. MassBio Board Chair Glenn Batchelder, Founder of Civitas Therapeutics, served as moderator.

"Foundations like the Multiple Myeloma Research Foundation or the Michael J. Fox Foundation do a good job in engaging the patient in the process," said Batchelder. "The more involved they are in the conversation, the more they'll understand what's available to them."

Also at the meeting, MassBio celebrated its 30th anniversary and unveiled a new mission statement: to advance Massachusetts' leadership in the life sciences to grow the industry, add value to the healthcare system and improve patient lives.

"We are taking time this year to reflect back on where we've been and the people and companies who have made us what we are today, while at the same time engaging in the

conversations that will define who we will be 30 years from now," said MassBio President and CEO Robert K. Coughlin. "This is an industry that in some ways has progressed light years since 1985. Today, Massachusetts is home to nearly 60,000 biopharma employees, 21 million square feet of lab space and companies with 1,500 drug candidates in the pipeline."

Coughlin recognized his predecessors as CEO of MassBio, Janice Bourque and former House speaker Thomas F. Finneran, who were both in attendance. He also installed seven new board members: Tim Clackson of ARIAD Pharmaceuticals, Chris Garabedian, Sam Guhan of Amgen, Melissa Bradford Klug of AMAG Pharmaceuticals, Antony Loevel of Sunovion Pharmaceuticals, John Orloff of Baxter BioScience and Michael Pellini of Foundation Medicine.

Massachusetts Secretary of Housing and Economic Development Jay Ash introduced himself to attendees, pledging the Baker administration's commitment to advancing the Massachusetts life sciences industry.

During the awards ceremony, Mark Levin, co-founder of Third Rock Ventures and an industry leader with 40 years of experience, was presented with the 2014 Henri A. Termeer Innovative Leadership Award for his passion for improving patient lives through disruptive technologies and innovative science.

"Mark personally mentored many of the leaders in Boston's biotech community," said Batchelder, who worked with Levin at Millennium Pharmaceuticals. "Delivery on his bold vision during those early days set the stage for innovation in our industry today."

"What a privilege it's been to work with so many visionaries in this industry," said Levin. "If you put together great people, you can do anything."

Levin, who started out in Silicon Valley and described Boston as evolving from "sleepy town" to the hub of activity, spoke about bridging territories in order to advance more therapies and cures.

"The tools and technology of our future are not all here in Massachusetts," said Levin. "How do we work with Silicon Valley or with China to do what's best for patients? We want to be No. 1, but we need to work together in this global setting to make a difference."

The Joshua Boger Innovative School of the Year Award was presented to Barnstable High School. Barnstable was selected as a BioTeach School in 2013 and has since established a "Biotech Bio-Wide" goal to bring biotechnology to all its students. The school has added a forensics and biotechnology class and a pathology and biotechnology class. Student interest and enrollment has

driven research projects.

A. Termeer Innovative Leadership Award. increased, and Barnstable has enriched its science program through new external partnerships and student-

Mark Levin was presented with the Henri

"I would love to continue my learning and will major in bioengineering next year," said Barnstable High student Sabrina Doherty. "Being able to go through the techniques in the labs, using the equipment we've been given, really helped solidify my decision to pursue this path."

Dr. Michael F. Collins, Chancellor of UMASS Medical School was presented with the MassBio Leading Impact Award for his work across the university to forge new and innovative partnerships with the life sciences industry. The award was accepted by Brendan O'Leary, Executive Vice Chancellor of Innovation and Business Development.





Keynote speakers were Andrew Lo, left, and Kathy Guisti.



Susan Hager, Walter Carney, David Altshuler and Jeff Elton discussed the opportunities of precision medicine.



Mark Bamforth and Robert K. Coughlin presented the MassBio Leading Impact Award to Brendan O'Leary, on behalf of Dr. Michael F. Collins.

MASSBIOED RECEIVES \$139,999 GRANT TO BRING BIOTEACH TO 10 HIGH SCHOOLS



Newton North High School students explored biotech at Genzyme.

The MassBioEd Foundation will expand its proven biotechnology education program, BioTeach, to 10 public high schools this year, thanks to a grant from the Massachusetts Life Sciences Center (MLSC).

MassBioEd will use the \$139,999 from the MLSC's STEM Equipment and Supplies Grant Program to provide 10 schools with professional development for teachers, curriculum for biotech labs, access to student career exploration experiences, and up to \$12,000 each for materials and equipment for school labs.

Lance Hartford, Executive Director of the MassBioEd Foundation is thrilled to see the program continuing to grow.

"MassBioEd is excited to expand our BioTeach program into 10 schools chosen through a competitive process," said Hartford. "By providing Massachusetts students with lab experiences in high schools across the state, we hope to inspire students to pursue educational opportunities and careers in the life sciences and biotechnology industry."

Susan Windham-Bannister, President & CEO of the MLSC, acknowledged the invaluable opportunities MassBioEd provides students.

"Investing in training the next generation of life sciences workers is a critical part of the Center's mission," said Windham-Bannister. "We want to create an interest in STEM careers among students all across the state, and at all levels. The Center's investments in equipment and supplies for training at high schools, both directly and through our partnership with the MassBioEd Foundation, are increasing interest in STEM among all of our students—regardless of socio-demographics or zip code."

The 10 schools funded by the MLSC's grant include:

- Avon Middle-High School, Avon
- Claremont Academy, Worcester
- Dennis-Yarmouth Regional High School, South Yarmouth
- Gloucester High School, Gloucester
- Lee Middle and High School, Lee
- Palmer High School, Palmer
- Smith Vocational and Agricultural High School, Northampton
- South Community High, Worcester
- Springfield High of Science and Technology, Springfield
- Weymouth High School, Weymouth

With the addition of these schools, the BioTeach program, recognized by the Massachusetts State STEM Council as a premier @Scale initiative, now reaches 204 schools in the Commonwealth.

Learn more about MassBioEd and BioTeach at www.MassBioEd.org.

NEW FOUR-PART FORUM SERIES





Harness the Power of Social Media

This spring, MassBio launched a new Forum series centered on the opportunities social media provides those in the life sciences to collaborate, create communities and contribute to a global conversation.

The Forums focus on building strategies, clinical trial recruitment, employee connections and patient/advocacy conversations as ways to harness the power of social media.

The first Forum in the series, "Growing a Dynamic Social Media Strategy" was held May 21.

The second Forum, "Clinical Trials in the Age of Social Media: Strategies for Increasing Trial Awareness & Patient Recruitment" will be held on June 11. Speakers will include:

- **Dawn F. Fenton**, MT(ASCP), Clinical Operations Lead, Global Clinical Operations, Biogen
- Aaron Fleishman, Patient Recruitment

Strategic Consultant, Product Innovation, BBK Worldwide

- Sally Okun, RN, Vice President for Advocacy, Policy, and Patient Safety, PatientsLikeMe
- Matthew Stafford, Assistant Director of the IRB, Boston Children's Hospital
- **Jeremy Chadwick**, PhD, Head Global Clinical Development Operations, Shire (Moderator)

Future sessions include:

Part 3: Social Media: Bridging Your Career, Your Employees & Your Company (July 29)

Part 4: Let's Talk: Open Dialogue with Patients & Patient Advocacy Groups (August 13)

These Forums, held at the MassBio offices from 8-10 a.m., are free for MassBio members and open to non-members for a fee of \$35. Learn more and register at www.MassBio.org.

Make a Difference in the lives of patients affected by kidney disease Join the global leader in dialysis healthcare where

you will collaborate with the brightest minds in the industry to creatively bring new, innovative products to those who need it most.

For a fast paced, exciting Regulatory Affairs Career, visit



SEE THE SAVINGS

MEMBERS REAP THE BENEFITS OF MASSBIO PURCHASING CONSORTIUM

There is power in numbers! By aggregating the purchasing power of the member companies within MassBio, the MassBio Purchasing Consortium allows members to have a strong presence in the marketplace so they can bring more to their bottom lines. MassBio continuously evaluates the need of member companies and the existing contracts to ensure the best value. In the last six months, MassBio has expanded the Purchasing Consortium to include lab prescription and safety eyewear and footwear through IPP, uniform and facility services through UniFirst, and access to scientific and business publications Nature, Nature Biotechnology, Science, Banker & Tradesman, Journal of Commercial Biotechnology, and DrugPatentWatch. Learn more and start saving today at www.MassBio.org.

CHECK OUT THE SAVINGS ACTUALLY ACHIEVED BY MASSBIO BIOTECH MEMBERS

Medium Biotech

Employees: 310 Items Purchased:

*Lab gases *Hazardous Waste Management

*Biomedical Waste Management

*Lab Supplies *Travel

*Shipping Services *Office Supplies

* Lab Equipment Maintenance

Est. List Price: \$ 5,584,138
Consortium Spend: \$ 3,947,333
Est. Savings: \$ 1,636,805
+Year-End Rebate: \$ 28,885

- MasBio Annual Dues: \$ 7,651

Bottom Line Savings: \$1,658,039

Large Biotech

Employees: 90,000 Items Purchased:

*Lab Equipment Maintenance

*Lab Gases

*Hazardous Waste Management

Est. List Price: \$ 3,104,947 Consortium Spend: \$ 2,369,473

Est. Savings: \$735,474 +Year-End Rebate: \$37,513 - MasBio Annual Dues: \$27,600

Bottom Line Savings: \$745,388

Stay tuned for examples of how associate members are saving!



MassBio President & CEO Robert K. Coughlin kicked off the Life Sciences Informatics conference with MassTLC President & CEO Tom Hopcroft.



Dimitris Agrafiotis of Covance, center, spoke about building data science departments with panelists Harpreet Singh, Joanna Brownstein, Elke Rundensteiner and Peter Covitz.

OPPORTUNITES EMERGE BETWEEN INDUSTRIES

INFORMATICS: from Page 1

"Once considered vendors or suppliers, data providers are now being seen as partners and collaborators," said Hisey. "Evidence is informing product design and patient care."

Paradigm4 CEO Marilyn Matz, who served as one of the event moderators, said access to data can sometimes be overlooked as an important factor when companies are locating or growing their businesses.

"Early-stage companies need access to space, capital and talent, but they also need access to data," said Matz.

During a discussion on the funding environment and emerging opportunities, investors shared their thoughts on how Massachusetts' LSIX entrepreneurs can differentiate themselves in a competitive market.

"We attach a lot of value to strategic

investors," said Eric Evans, who serves on the Executive Committee of Mass Medical Angels. "The involvement of a company like Microsoft or Google gives validation to an idea. It shows there's interest, maybe even a need."

Another panel discussed how to source and train talent and organize and integrate data science teams or departments.

"We cannot conceive solutions to biomedical problems without domain expertise," said Covance Vice President and Chief Data Officer Dimitris Agrafiotis, calling software engineering a top skill set of today's students and emerging workforce.

A final panel examined innovative partnerships and ways to bridge science with IT and informatics. Robert McBurney, CEO of the Accelerated Cure Project for Multiple Sclerosis and Dave King, Founder & CEO of the Cambridge startup Exaptive, described their

partnership. Exaptive is helping to integrate and analyze the data contained in the Accelerated Cure Project's ever growing repository of research studies.

"For the past decade, we've been trying to reinvent the way biomedical research is done by identifying and breaking down barriers that hinder research," said McBurney. "We've created a bio depository, virtual collaborations and a large amount of data that we hope will unlock breakthroughs to a cure."

With Exaptive, the Accelerated Cure Project is able to cross-reference their data with existing research, and analyze results using interactive visualization techniques from inside and outside the medical field, all in real-time.

"We sometimes put value on something being faster or more efficient, but these tools don't just get more things done, they get different things done," said King. "They give you different products."

King also said an important aspect of data visualization is not just in discovery, but in communication. Stephen Cleaver, Executive Director of Informatics Systems for Novartis, agreed.

"The key is translating raw data into a system that allows you to answer relevant scientific questions," said Cleaver.

As innovative partnerships within the industries of life sciences and informatics continue to emerge, yielding mutually beneficial results and new possibilities, King said finding the right match, or the right relationship, is essential.

"Just as personalized medicine targets the right treatment for the right disease, we're seeing similar matches between the specific flavor of a start-up and that of a partnering company," said King.



SAVE THE DATE: 2015 CRO/CMO SYMPOSIUM FRIDAY, NOVEMBER 13, 2015
AT THE RENAISSANCE BOSTON WATERFRONT HOTEL

Registration is now open! Learn more and register at www.MassBio.org. Sponsorship and exhibitor opportunities are available. Contact Elizabeth Steele at elizabeth.steele@massbio.org or 617-674-5100.



PRESORT-STD U.S. POSTAGE PAID CAMBRIDGE, MA 02142 PERMIT NO. 981

PATIENT

NAVIGATING UNCHARTERED WATERS

Woburn family finds answers, quality care through the Genesis Foundation for Children and The Feingold Center



Thanks to the care Michael Sawyer receives from The Feingold Center, he is able to live an active lifestyle.

By Meaghan Casey

Every year, 1 in 33 children is born with a physical, intellectual or genetic disorder. Michael Sawyer, now 17, was one of those statistics.

"As developmental milestones go, he was meeting them up until he was about a year old," said his father, Richard Sawyer. "When he still wasn't walking six months after that, we aggressively started looking for answers. It was unchartered waters for us."

Richard and his wife, Kathleen, adopted Michael from South Korea when he was 4 months old. It was later, through genetic testing, that he was diagnosed with a genetic disorder that typically causes severe intellectual disability. Affected individuals usually have weak muscle tone, breathing and swallowing difficulties and cognitive and oral communication problems. It can also lead to heart defects—which Michael has not experienced. The disorder is caused by a chromosomal deletion of genetic material and affects approximately 1 in 10,000 people. Treatment is mainly aimed at reducing the severity of symptoms and monitoring the patient's general health.

Early on, the family met with Dr. Murray Feingold, the founder of The Feingold Center for Children, which provides diagnosis and treatment for children born with intellectual and developmental disabilities and genetic disorders. Dr. Feingold has been

treating children with genetic diseases for more than 40 years and has been on the faculty of Tufts, Harvard and Boston University medical schools.

"The biggest stress on a family is the unknown," said Richard. "The Feingold Center minimizes that stress, and we'll be eternally grateful for that. By getting the correct diagnosis, we were able to identify service providers that have been a benefit to Michael moving forward."

Michael still receives his primary care from The Feingold Center at its location at Boston Children's Hospital at Waltham, and is regularly examined and monitored for high-risk problems. Because many of the children they treat require the care of numerous specialists, the staff at the center also coordinates those appointments so that patients are seen by more than one specialist at the same visit.

"It's given us peace of mind that he's gotten the finest care from some of Boston's top doctors," said Richard.



Dr. Murray Feingold

The Genesis Foundation for Children (formerly known as the Genesis Fund) primarily funds The Feingold Center. The specialized care and coordination provided to patients with complex genetic disorders is extremely costly and not covered by insurance, which is why the funding is so essential. The center and its satellite clinics would not be able to operate without it. Funding is also given to support the foundation's therapeutic arts and recreational programs on Cape Cod. Through 60,000 patient visits, the foundation has provided diagnosis, care and guidance to many grateful families since its inception in 1982.

Michael is thriving as a junior at Woburn Memorial High School, where his younger brother, Benjamin, is also a student. In the school's Transition Education Program, Michael is benefitting from functional life and activities of daily life (ADL) skill training. Accompanied by a job coach, he also works one day a week at CVS through the program's community-based vocational training. After high school, he will continue to participate in vocational training opportunities available to the city's young adults ages 18-22. Outside of school, he enjoys playing soccer, baseball and basketball.

"He's definitely meeting his potential and we couldn't be prouder," said Richard.