



Page 3 | MEET OUR NEW BOARD CHAIR



Page 8 | RARE IN COMMON

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MassBio news

MASSACHUSETTS BIOTECHNOLOGY COUNCIL

POWER PLAYERS

**MORE THAN 450
LIFE SCIENCES
PROFESSIONALS
JOIN MASSBIO
AT THE 2016
ANNUAL MEETING**

Pages 4-5

Gov. Charlie Baker greets 16-year-old Kate Marshall, a cystic fibrosis patient and advocate, at the Annual Meeting.

PHOTO: SEAN BROWNE



MASSACHUSETTS BIOPHARMA INDUSTRY HIRING AT RECORD RATE

New MassBioEd report shows industry posted 2,643 jobs

The Massachusetts biopharma industry is hiring at a record rate, with the highest number of online industry job listings as compiled by Burning Glass Technologies in the first quarter of 2016 than has been posted in any other quarter in the last three years, according to MassBioEd's newest 3-Month Job Trend Report.

MassBioEd produces a three-month report on biopharmaceutical job trends each quarter of the year. The report compares online job listings for the most current three-month period with job listings for the same three-month period of the previous year to determine trending in job listings. Findings show increased job postings at every degree level requirement.

Key findings from the report for quarter one of 2016 include:

- The Massachusetts biopharmaceutical industry is in the midst of a prolonged expansion cycle;
- The three-month average for Q1 2016 was the highest on record – with 2,643 industry job posts recorded online during that span – significantly higher than in previous three-month periods;
- January and March of 2016 were the two highest months for job postings since the beginning of 2014,

See **JOB TRENDS** Page 7

VALUING THE STRENGTH OF OUR PATIENTS, LEADERS



ROBERT K. COUGHLIN

Thank you to all who joined us at this year's Annual Meeting, which continued critical conversations on defining value in medical innovation. We heard from an inspiring young woman, Kate Marshall, who shared with us her journey as a cystic fibrosis patient and high school athlete, as well as Dr. Tony Coles, an industry leader dedicated to transforming drug discovery for neurodegenerative diseases. It was also a pleasure to welcome Gov. Charlie Baker, Congressman Richard Neal and Health and Human Services Regional Director Rachel Kaprielian.

This year also marked a changing of the guards for our Board of Directors. Glenn Batchelder has successfully completed a two-year term as our

chairman, and it has not been a quiet two years. It was under Glenn's leadership that we launched Impact 2020, a strategic report that has put MassBio on a solid path to serve the industry for the next several years. It was in Glenn's tenure that we updated MassBio's decades-old mission statement, to clearly and concisely state our goal to grow the industry, add value to the healthcare system and improve patient lives. And it is with Glenn's guidance we have grown to offer broader and deeper services to our entire membership. In his place, we are thrilled to welcome and congratulate our new chairwoman, Abbie Celniker, CEO of Eleven Biotherapeutics. You will learn more about Abbie in our Q&A, but she has been in our industry for more than 25 years with companies such as Alexion, Taligen, Novartis, Millennium, Wyeth, Genetics Institute, Genentech and the University of Arizona Cancer Center. Needless to say, she is significantly overqualified for this position, and we are so thrilled she is stepping up to help guide

MassBio over the next two years.

I look forward to connecting with many of you at the BIO International Convention in San Francisco. Please make sure to stop by the Massachusetts Pavilion and visit us. I am so proud to represent companies, researchers and executives of the Massachusetts life sciences community—a community that is pushing the leading edge of science, tricking the body into editing disease right out of its own DNA and innovating new business models that allow for the laser-focused deployment of resources to move ideas into testing as quickly and cost-effectively as possible.

Thank you as always for joining us in a shared commitment—to work with patients to define desired outcomes and endpoints and to rid the world of disease.

Robert K. Coughlin is President & CEO of MassBio.

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Croda
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Disease Diagnostic Group
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Genentech
Gilead Sciences
Gritstone Oncology
Hebecell
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Longboat Clinical
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Microbiology Research Associates
MicroMedicine
Micros Northeast
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Olink
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PerkinElmer
Piper Therapeutics
Precidiag
Quiet Therapeutics
Quintiles
Relay Therapeutics
Ribon Therapeutics
Sherbrooke Innopole
Synlogic
Ten Bridge Communications
Timmerman Report
Tobin Scientific
Torreya Insights
TTE Laboratories
Vedanta Biosciences
Xios Therapeutics
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Joseph Fazio
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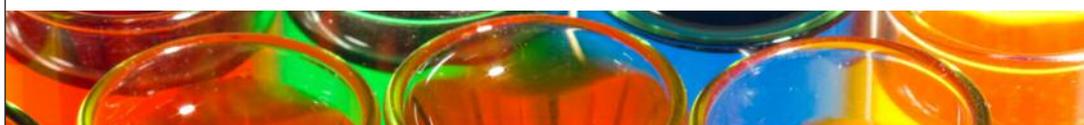
Kendalle Burlin O'Connell
VP of Member Services

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2015 MASSACHUSETTS IPOS



FLEXPharma	\$86 M	Lantheus Holdings	\$65 M
EyeGate pharma	\$4 M	SERES THERAPEUTICS	\$134 M
INOTEK PHARMACEUTICALS	\$40 M	CHIASMA	\$101.8 M
blueprint MEDICINES	\$147 M	DIMENSION THERAPEUTICS	\$72 M
CoLucid pharmaceutical, inc.	\$55 M	Voyager THERAPEUTICS	\$70 M
catabasis	\$60 M	WAVE LIFE SCIENCES	\$102 M
COLLEGIUM Pharmaceutical	\$70 M		

Note: Figures refer to "offer amounts" (investment secured) at time of IPO
Source: Nasdaq.com, BioSpace



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MASSBIO WELCOMES NEW BOARD MEMBERS

MassBio added five life sciences executives to the organization's Board of Directors and elected new board leadership at the MassBio Annual Meeting.

MassBio members elected Abbie Celniker, CEO of Eleven Biotherapeutics, as the new Chair of the Board of Directors and David Lucchino, Co-Founder of Frequency Therapeutics, as the new Vice Chairman. MassBio re-elected Michael O'Hara, Partner at Deloitte, as Treasurer and elected Chuck Wilson, President and CEO of Unum Therapeutics, as the new Clerk. Lawrence Wittenberg, senior partner in Goodwin Procter's Technology Companies & Life Sciences Group and Co-Chair of the firm's Healthcare Technology and Services Practice, continues on the Executive Committee as counsel.

Joining the board this year are Christopher de Souza, Director at Broadview Ventures; Michael Ehlers, Executive Vice President, Research and Development at Biogen; Michele Galen, Senior Vice President and Head of Communications & Public Affairs at Shire plc; Michael J. Ruggiero, Vice President of U.S. Government Affairs and Policy at EMD Serono, Inc.; and Kumar Srinivasan, Vice President, Scientific Partnering and Alliances and Site Head, R&D Boston at AstraZeneca.

"We are thrilled to welcome our new board members and excited for the significant breadth and depth of expertise that comes with electing these industry executives to the MassBio Board of Directors," said MassBio President & CEO Robert K. Coughlin. "We rely on our board to represent and advocate for life sciences organizations and their needs, as well as the needs of various stakeholders. We appreciate the time they devote to building the Massachusetts supercluster through MassBio."

Christopher de Souza, Director at Broadview Ventures, shares responsibility for the day-to-day operations of Broadview Ventures, leveraging 20 years of experience in biopharmaceutical R&D, business development and corporate strategy. Prior to joining Broadview Ventures, de Souza was Vice President of Business Development at SkyePharma US Inc., he



founded a business development consulting practice, and he was Director of Strategic Alliances at Novartis in the Metabolic and Cardiovascular Diseases group. De Souza received an MBA from Rutgers University and a Ph.D. in physiology from Louisiana State University. He completed his post-doctoral training at "The Upjohn Company" and the Joslin Diabetes Center/Harvard Medical School.

Michael Ehlers is Executive Vice President, Research and Development at Biogen. Prior to joining Biogen, he served as Senior Vice President for BioTherapeutics Research & Development and Chief Scientific Officer for Neuroscience & Pain at Pfizer, Inc. where he oversaw the operation and function of Pfizer's Cambridge and Boston research sites. Prior to joining Pfizer in 2010, Ehlers



was the George Barth Geller Professor of Neurobiology and an Investigator of the Howard Hughes Medical Institute at Duke University Medical Center where he pioneered studies on neuronal organelles and the trafficking of neurotransmitter receptors. Ehlers earned his bachelor's degree in chemistry from Caltech and holds M.D. and Ph.D. degrees from the Johns Hopkins University School of Medicine.

Michele Galen joined Shire in April 2015 as Senior Vice President and Head of Communications & Public Affairs, reporting to the CEO, and serving as an extended member of the Shire Executive Committee. A lawyer and journalist, Galen most recently served as a Managing Director for MPM Capital and as a communication advisor and executive coach to corporate and global health clients.



Galen spent 14 years at Novartis in global leadership roles, including as Chief Communications Officer. Galen has a bachelor's from George Washington University, a J.D. from New York University School of Law, and master's in Journalism from Columbia University.

Michael J. Ruggiero is Vice President of U.S. Government Affairs and Policy at EMD Serono, Inc. In this role, Ruggiero leads the company's government policy strategy and engagement with policymakers, industry associations, patient and provider groups, and other stakeholders. Ruggiero sits on the US Country Leadership Team and the Global Government Affairs & Policy Leadership Team. Prior to joining EMD Serono in 2013, Ruggiero was Vice President of Government Strategy for a top-20 global pharmaceutical company. Prior to that, Ruggiero was a healthcare attorney and lobbyist in Washington, D.C. Ruggiero earned a B.A. from Syracuse University and a J.D. from Georgetown University Law Center.



Kumar Srinivasan is Vice President, Scientific Partnering and Alliances and Site Head, R&D Boston at AstraZeneca. Prior to joining AstraZeneca, Srinivasan was Chief Business Officer at Probiobug AG, then a private venture-funded German company developing novel treatment for Alzheimer's and inflammatory diseases. Prior to joining Probiobug, Srinivasan was Vice President, Global Business Development at Wyeth Pharmaceuticals, where he led business development and licensing activities for pre-phase two opportunities. Srinivasan earned his MBA from the University of Chicago's Booth School of Business, and a Ph.D. in Organic Chemistry from Case Western Reserve University, Cleveland. He completed his postdoctoral training at California Institute of Technology.



Srinivasan was Vice President, Global Business Development at Wyeth Pharmaceuticals, where he led business development and licensing activities for pre-phase two opportunities. Srinivasan earned his MBA from the University of Chicago's Booth School of Business, and a Ph.D. in Organic Chemistry from Case Western Reserve University, Cleveland. He completed his postdoctoral training at California Institute of Technology.

Q&A WITH ABBIE CELNIKER

Chair of the
MassBio Board &
CEO of Eleven
Biotherapeutics



Q What is the current climate for life sciences company formation in Massachusetts and how do you see that changing in the next few years?

A The climate continues to be excellent and the amount of local innovation, talent and resources, financial and otherwise, make Massachusetts the perfect place to start a company. This is further supported by the number of larger pharma and biotech companies that have established R&D hubs in Massachusetts. The natural life cycle of smaller companies partnering with larger ones allows the industry to strengthen and grow and should continue for the foreseeable future.

Q When you took the helm as chair, you set out gender diversity as one piece of your platform. How can MassBio be a leader in addressing diversity in the life sciences industry?

A The first step that MassBio has taken is acknowledging the lack of gender diversity at the Executive and Board level. MassBio can play a central role in catalyzing the critical networking amongst industry executives and investors that is essential for increasing the awareness of highly capable and experienced women. Finally, we can

all gain a better understanding of the current settings which may play a role in why women are not accepting more roles with increasing responsibility.

Q What is the most critical challenge or opportunity on the horizon for MassBio and its member companies?

A Both a challenge and opportunity is the massive amount of data and information our industry accumulates. We have an ecosystem with hospitals, institutions, companies and CROs all generating and collecting overlapping data points. This information has to be harnessed to better identify ways to address unmet needs of patients through more personalized therapies.

Q What is MassBio's role in communicating the value of treatments and cures?

A MassBio's role is orientation and education about the value of a treatment versus a price of a treatment. When an innovative treatment makes a difference in a patient's life that is recognized by that patient and his or her physician and family, it has value. MassBio works closely with patient advocacy groups and policy makers to assure a collective voice and awareness of the total impact of the value that a treatment has created for all stakeholders.

THE PROMISE AND VALUE OF MEDICAL INNOVATION



From left, MassBio President & CEO Robert K. Coughlin opens the event; students from Diman Regional Vocational Technical High School are presented with the Joshua Boger Innovative School of the Year Award; Health and Human Services Regional Director Rachel Kaprielian addresses the crowd; Editas CEO Katrine Bosley speaks about pricing and value; Mike Huckman of Pure Communications interviews Dr. Tony Coles, CEO of Yumanity Therapeutics; and Alnylam CEO John Maraganore is presented with the Henri A. Termeer Innovative Leadership Award.

PHOTOS: SEAN BROWNE

2016 Annual Meeting inspires, challenges attendees to be patient-driven

BY MEAGHAN CASEY

There are heroes among all of us—heroes who fight a daily battle against the most debilitating diseases, and heroes in labs and manufacturing facilities who work tirelessly to bring treatments and cures to those who need them most.

On March 31, the MassBio community was introduced to one such hero, 16-year-old Kate Marshall. A high school honors student, accomplished athlete and cystic fibrosis (CF) advocate, Marshall was diagnosed with CF shortly after she was born.

“The 30 pills I swallowed every day and the vest I used for breathing—it was all I knew,” said Marshall, a York, Maine resident. “Those who battle CF are brave, resourceful and wise beyond our years.”

Despite her diagnosis, Marshall lived an active lifestyle throughout her childhood and made a name for herself on the soccer field. It wasn’t until she was hospitalized at age 12 that the disease began to take its toll.

“Pushing myself physically and athletically always came naturally, but all of a sudden there I was, wearing a PICC (peripherally inserted central catheter) line in the halls,” said Marshall. “My lung function continued on a downward spiral and chipped away at my health.”

In May 2015, Marshall testified before an advisory panel to the FDA in favor of approval of Orkambi, a combination therapy developed by Vertex Pharmaceuticals. It helps in correcting the mutated genes—a novel therapeutic approach designed to treat the root cause of cystic fibrosis instead of just the severity of symptoms. It builds on the success of the company’s first CF drug, Kalydeco, which treats patients with one of 10 mutations of the CF gene. Orkambi, which



Kate Marshall, 16, delivers the opening keynote address.



Gov. Charlie Baker addresses patient access, drug pricing and investing in qualified individuals.

combines Kalydeco with a new drug, can treat patients with a far more common gene mutation shared by half of all patients. Orkambi was approved on July 2, 2015 and Marshall took her first dose 16 days later, on July 18. Her health has since stabilized and her FEV1—the Forced Expiratory Volume after 1 second of blowing out—has increased by 11 percent, which is a significant gain. She said she feels stronger and faster and did not miss a single varsity soccer practice or game this year.

“Thank you, Vertex,” Marshall said. “I’m so grateful, but until there’s a treatment for all CF patients, regardless of genotype, there won’t be a celebration. Time is our worst enemy, but we’re so close to being able to manage one of the worst diseases known to mankind. I look forward to a day when every patient can say, ‘my CF is under control,’ or better yet, ‘I used to have CF.’”

Her remarks were met with applause and a standing ovation at MassBio’s 2016 Annual Meeting, held at the Royal Sonesta Hotel in Cambridge. Marshall gave the opening keynote address, kicking off the two-day event that was attended by more than 450 professionals in the life sciences industry. Conversations covered subjects such as price and value, advanced manufacturing, digital healthcare, technology in clinical trials, innovative pricing and more.

Editas CEO Katrine Bosley addressed the issue of societal expectations regarding the value of innovative therapies.

“The most compelling case in the past year has been the development of a drug to cure hepatitis C,” said Bosley. “Here we have one pill over a 12-week course of therapy and it’s cured. That’s spectacular scientifically, but what made headlines was the price of the drug.”

John Glasspool, Executive Vice President and Head of Corporate Strategy at Baxalta, reflected on how the expectations are often asked because the industry’s value framework is so vastly different from what most of us are used to when shopping for retail products.

“In the consumer world, people make choices—investing in a luxury watch from Switzerland or going with a model from Singapore,” Glasspool said. “In healthcare, people can’t make that choice.”

Earlier in the day, Gov. Charlie Baker set the tone for a thoughtful discourse on patient access and drug pricing and shared his plan to invest heavily in areas that will help

the life sciences industry recruit qualified individuals.

“The crown jewel you’ve created—this industry—is something we want to continue,” said Baker. “We can and want to be a collaborator. We need to make sure the investments we make in education, transportation and energy are the ones that leverage the investments you’re making and ensure success right here in Massachusetts.”

MassBio President & CEO Robert K. Coughlin shared the latest statistics of the Massachusetts supercluster: it is home to more than 60,000 biopharma employees, 22 million square feet of lab space and companies with 1,500 drug candidates in the pipeline. Eight of the 42 drugs approved by the FDA last year were researched, developed or manufactured in the Commonwealth.

“The work taking place here has us moving fast forward toward breakthrough scientific advancements—the types of discoveries that will ultimately lead to cures,” said Coughlin.

At the annual awards luncheon, MassBioEd Executive Director Peter Abair presented Diman Regional Vocational Technical High School with the 2015 Joshua Boger Innovative School of the Year Award. The school earned the award for its excellent biotech science education program. Students credited the MassBioEd BioTeach program for inspiring their interest in biotechnology.

“Before last year, I had no idea what biotechnology was,” said Diman sophomore Kylie Cooper. “Having the opportunity to use the latest equipment in the field was something not many people are able to do. This isn’t just textbook learning. It’s hands-on. We’re performing real experiments and discovering answers that are unknown. To me, that’s what science is all about, and that’s why I see in future in biotechnology.”

The Henri A. Termeer Innovative Leadership Award was presented to Alnylam CEO John Maraganore for his commitment to growing in Massachusetts and leading the global conversation on the value of medical innovation. His company announced in February it will develop a 130,000-sq-ft manufacturing facility in Norton, Mass. and hire approximately 150 more full-time employees. Under his tenure, Alnylam has also advanced an entirely new class of innovative medicines—RNAi therapeutics—that have the potential to treat disease in a fundamentally different way.

“As I reflect on my time here, there’s a remarkable spirit of collaboration among the leaders in this cluster,” said



Amir Nashat, Paris Panayiotopoulos, Daniel Durham and moderator Jeanne Blake discuss the 2016 National Landscape.

Maraganore. “I’ve never been more excited about the future of this industry. The pace has never been faster, and the understanding has never been greater. We’re seeing new pathways and an increase in approvals, and the science is informing us to create products that are better than ever before. One thing we need to do is make sure generic drugs can go to market sooner, so the breakthroughs today can be accessible to our children and grandchildren.”

The Leading Impact Award was presented to Novartis, which has steadily grown since moving its global research headquarters to Cambridge in 2002 and is currently the third largest life sciences employer in the state.

The second day of the event started out with back-to-back breakout sessions, a panel on the 2016 National Landscape and remarks from Congressman Richard Neal, who shared his thoughts on drug pricing, tax reform and the political season.

Health and Human Services Regional Director Rachel Kaprielian offered hope that “healthcare is becoming more about wellness than sickness” and pledged her support to the industry. Dr. Tony Coles, Chairman and CEO of Yumanity Therapeutics, gave the closing keynote and reflected on the fact that the conversation of the national political campaign can provide an opportunity for the industry to evolve and

change—particularly in regards to business models and creative approaches to pricing.

“If we choose to put our head in the sand, and ignore that innovations are required not just in science and the diseases we go after, but also in the way we model our business and the way we deliver returns to shareholders, we’ll miss an opportunity,” Coles said.

Coughlin agreed with his sentiments, bringing further attention to the headwinds the industry faces in a national conversation about the cost of therapies, just as it is poised to bring more personalized medicines, advanced diagnostics and cures to market.

“We have taken shots from political candidates who find our industry a convenient target during campaigns that focus on soundbites instead of insightful policies,” Coughlin said. “We have been put on the defensive by the health plans in a nationwide effort to divert attention from the significant increases in out-of-pocket costs patients face as a result of cost-shifting and high-deductible plans. I say bring it on. We—the Massachusetts life sciences community—are innovators. There is no industry better positioned to make a case for the role of value in the healthcare system and the value of medical advancement to society as a whole.”

SEE THE SAVINGS

MEMBERS REAP THE BENEFITS OF MASSBIO PURCHASING CONSORTIUM

There is power in numbers! By aggregating the purchasing power of the members 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. Recently, MassBio expanded the Purchasing Consortium to include technology hardware and services through Micros Northeast and added *Timmerman Report* to its industry publications offering.

Learn more and start saving today at www.MassBio.org.

CHECK OUT THE SAVINGS ACTUALLY ACHIEVED BY MASSBIO BIOTECH MEMBERS

PURCHASING CONSORTIUM CASE STUDY		PURCHASING CONSORTIUM CASE STUDY	
<i>Employees: 20 (Small Biotech)</i>		<i>Employees: 145 (Medium Biotech)</i>	
Items Purchased:		Items Purchased:	
> Lab Equipment Maintenance	> Lab Supplies	> Lab Equipment Maintenance	> Lab Gases
> Biomedical Waste Management	> Office Supplies	> Biomedical Waste Management	> Lab Supplies
> Hazardous Waste Management		> Hazardous Waste Management	> Office Supplies
Consortium Spend	\$ 486,553	Consortium Spend	\$ 5,414,526
Est. Savings	\$ 309,393	Est. Savings	\$ 3,474,384
+ Year-End Rebate	\$ 4,510	+ Year-End Rebate	\$ 75,292
- MassBio Annual Dues	\$ 1,750	- MassBio Annual Dues	\$ 8,645
Bottom Line Savings	312,153	Bottom Line Savings	3,541,031

*All spend and savings amounts are based on 2015 figures and estimated using average list prices and discounts provided by suppliers.

NEW THREE-PART FORUM SERIES: DIGITAL HEALTHCARE



What does digital healthcare mean for life sciences industry professionals? How does it affect patients? Why has it become such a hot topic?

To address these questions and more, MassBio is hosting a new Forum series centered on digital healthcare this June through August. This series will feature industry leaders, policymakers, patients, providers and investors as they share their insights on the challenges and opportunities of digital healthcare.

JUNE 21

Part 1: The Digital Healthcare Landscape

Fueled by advances in technology and the pressing need for healthy outcomes, digital health dominates today's healthcare conversation. Learn more about the digital healthcare landscape from a digital health futurist and panelists representing entrepreneur, investor and pharma perspectives.

JULY

Part 2: "Mobilizing" Clinical Trials

Wearable devices, mobile applications for smartphones, sensors and other digital health technologies have the potential of revolutionizing clinical trials and natural history studies. Learn how new technologies can support real-time trial oversight and accurate, efficient and timely data capture.

AUGUST 4

Part 3: Commercialization & Beyond

Join industry experts, patients and clinicians to discuss pricing, reimbursement, regulatory requirements, pharmacoeconomic evaluation and patients' lives in the digital world.

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.



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POLICY UPDATE

In April, MassBio President & CEO Bob Coughlin and Chairman Glenn Batchelder joined dozens of industry representatives and other stakeholders to oppose Massachusetts Senate Bill #1048, An Act To Promote Transparency and Cost Control of Pharmaceutical Drug Prices.

The bill would require manufacturers of drugs included in a “critical prescription drug list” to disclose certain information relating to the price of those drugs. The bill would also authorize the Massachusetts Health Policy Commission to cap drug prices it determines to be “significantly high.” Similar prescription drug price transparency bills have been filed in a growing number of states, including California, Colorado, New York, North Carolina, Oregon, Pennsylvania, Virginia and Vermont.

Instead of taking a comprehensive and critical look at total healthcare expenditures, Senate Bill 1048 focuses attention on a snapshot of upfront costs for innovative and breakthrough therapies that, in the longer term, can not only save money in the health care system, but immeasurably improve patients’ lives. And Senate Bill 1048 does this with the side effect of needlessly raising the administrative burden on the innovative companies responsible for much of the Commonwealth’s economic growth today and in the future. In the end, it won’t help patients one bit.

We agree that the current healthcare system—one that allows the newest, most effective medicines to be placed on the most expensive tiers requiring growing out-of-pocket payments from our sickest patients—needs to be fixed. We are mindful of the fiscal impacts of new and innovative medicines on strained budgets.

However, Senate Bill 1048 does nothing to address either problem. Instead, it mandates the collection of information payers want you to believe should be sufficient for measuring reasonable pricing, but in fact provides an incomplete picture of true healthcare cost while also creating potential additional barriers to patient access. Senate Bill 1048 would impose a very real and unreasonable burden on innovative companies with no public benefit—and in the process will stifle investment in research, jeopardizing the discovery of the next generations of treatments, and harming patients in a very real way.

The Joint Committee on Healthcare Financing has until June 1 to take action on the bill. MassBio is engaging with stakeholders on all sides of the issue—our member companies, BIO, PhRMA, the health plans and providers—in order to ensure the Commonwealth does not adopt policies that will limit patients’ access to the treatments and cures they need.

We encourage our members to weigh with their state legislators in opposition to Senate Bill 1048.

For more information on this and other MassBio policy priorities, visit www.MassBio.org.

MASSACHUSETTS BIOPHARMA INDUSTRY HIRING AT RECORD RATE

JOB TRENDS: from Page 1

when the data was first collected by MassBioEd; and

- The 12-month growth rate in job postings for the Massachusetts biopharmaceutical industry was 37.8 percent.

The 3-Month Report is part of MassBioEd’s ongoing Digest of Biotech Jobs Trends in Massachusetts, which also includes Briefs (which, for 2015, focused on entry level job position trends) and an Annual Jobs Trends Forecast.

MassBioEd’s job trends initiative grew out of MassBio’s Impact 2020 Report which identified a challenge for companies as they grow and thrive in Massachusetts: data on and access to the right workforce. MassBioEd and MassBio share a commitment to collecting and sharing data, and convening industry and education leaders to promote collaboration and better alignment on workforce development needs.

To see the full report and other job trends data, visit www.MassBioEd.org.



The Creedon family enjoys some much-needed vacation time in Florida, just prior to Luke’s heart surgery.

RARE PATIENT AWAITS DIAGNOSIS

PATIENT: from Page 8

“They have so much strength and kindness and the biggest of hearts. Hopefully viewers take away how much love and life comes with the rare space.”

The intended audience is two-fold. For those who are familiar with or impacted by a rare disease, Shakarian hopes the film empowers them. For doctors and representatives from pharma and insurance companies, she hopes it makes them think about rare diseases differently.

“Every rare disease is different, but they all have rare in common,” Shakarian said, referring to the film’s title. “We want the stories in the film to give people the inspiration to keep fighting and advocating to show everyone that there’s hope for a better future.”

“Before, we didn’t think there was anyone who understood what we are going through, but this film and the premiere event introduced us to a network of people just like us that fight and advocate each and every day,” said



Luke Creedon has undergone multiple surgeries and tests in his path to diagnosis and treatment.

Janis. “They get it and live it just like us and that is a powerful and inspiring thing, to know we are not alone and part of something larger. It’s very reassuring

to see parents with older children who have a system and who are doing well. I found them especially to be a resource.”

The Creedons were connected to Rare in Common through Patricia Ferland Weltin, CEO and founder of Rare Disease United Foundation. They had also participated in Beyond the Diagnosis, a rare disease art exhibit at Harvard Medical School.

“Rare in Common” premiered in Cambridge and has since been submitted to a number of film festivals. At South by Southwest in Austin, the film was shown as part of a session on building rare disease communities. Lisa Hazen, chief strategy officer at Cambridge Biomarketing, served as one of the presenters, examining how digital innovation can provide an incredible opportunity to unite isolated groups of people together for a common cause—discovering fellowship, engendering hope and taking action to pursue their health as individuals and as a collective.

To learn more, visit www.rareincommon.com.



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WAITING FOR A DIAGNOSIS

Rare disease patient's journey documented in film

BY MEAGHAN CASEY

Since Rare Disease Day was launched in 2008, there have been thousands of events on the last day of February each year, bringing new awareness to hundreds of thousands of people. Yet, for more than 30 million Americans, it's a far cry from a one-day event. For them, Rare Disease Day is every single day.

Brockton residents Seth and Janis Creedon understand the reality of living with a rare disease all too well. They have spent the last four years seeking a diagnosis for their young son, Luke, who has various symptoms of a connective tissue disorder that doctors cannot identify.

"There are over 7,000 diagnosed rare diseases, and we still don't even have a hole to put Luke's peg," said Janis.

A disease is defined as rare if it affects fewer than 200,000 people in the U.S. at any given time. Living with one can be frightening and isolating—especially if that disease goes undiagnosed. The complex nature of rare diseases, coupled with limited access to treatment and services, means that family members are often the primary source of solidarity, support and care for their loved ones.

While the Creedons are still navigating the unknown, the closest comparison to Luke's disorder would be Marfan syndrome, which also affects the body's connective tissue and limits its ability to grow and develop properly. Features of the disorder are most often found in the heart, blood vessels, bones, joints and eyes, but it does not affect intelligence. Janis has found the same to be true for her son.

"The only thing that has proved to be a waste of time was an MRI," she said. "There's nothing wrong with his brain. It's not a muscle. That's been the only thing that came back fine."

She describes Luke as fragile because of his lack of balance and muscle development. He has had respiratory and cardiac problems, as well as sleep apnea. Feeding him has also been a huge challenge due to issues with swallowing.

"After he was born, we knew pretty immediately something was wrong," said Janis. "He had a lot of feeding problems and almost a cleft palate. We couldn't get him to gain any weight, he had no muscle tone and he slept all the time."

At 6 months old, Luke was referred to Boston Children's Hospital to see specialists in neurology, growth, nutrition and genetics.

"By that point, he weighed 13 pounds and developmentally was still like a newborn," Janis said.

He began receiving physical therapy services almost immediately. Janis said she wasn't even sure if he would be able to walk, but he completed that milestone at age 2½.

"He's making progress, but we're always discovering new challenges," said Janis, explaining Luke is now seeing as many as 18 specialists. She credits the dedication of Dr. David Chung, his primary care physician, and Dr. Sharon Smith, a specialist in genetics and genomics, for much of his progress.

Recently, Luke had surgery to remove his tonsils and doctors also took out half an inch of his tongue on both sides to stop his tongue from blocking his airway in his sleep. He will soon be undergoing another surgery to close a hole in his heart.

"He's a trooper," said Janis. "He has such a wonderful disposition, it's just amazing. We'll go to the hospital and he'll ask, 'Am I sleeping here or am I getting a cookie?' That's how he distinguishes an overnight visit from a routine check-up."

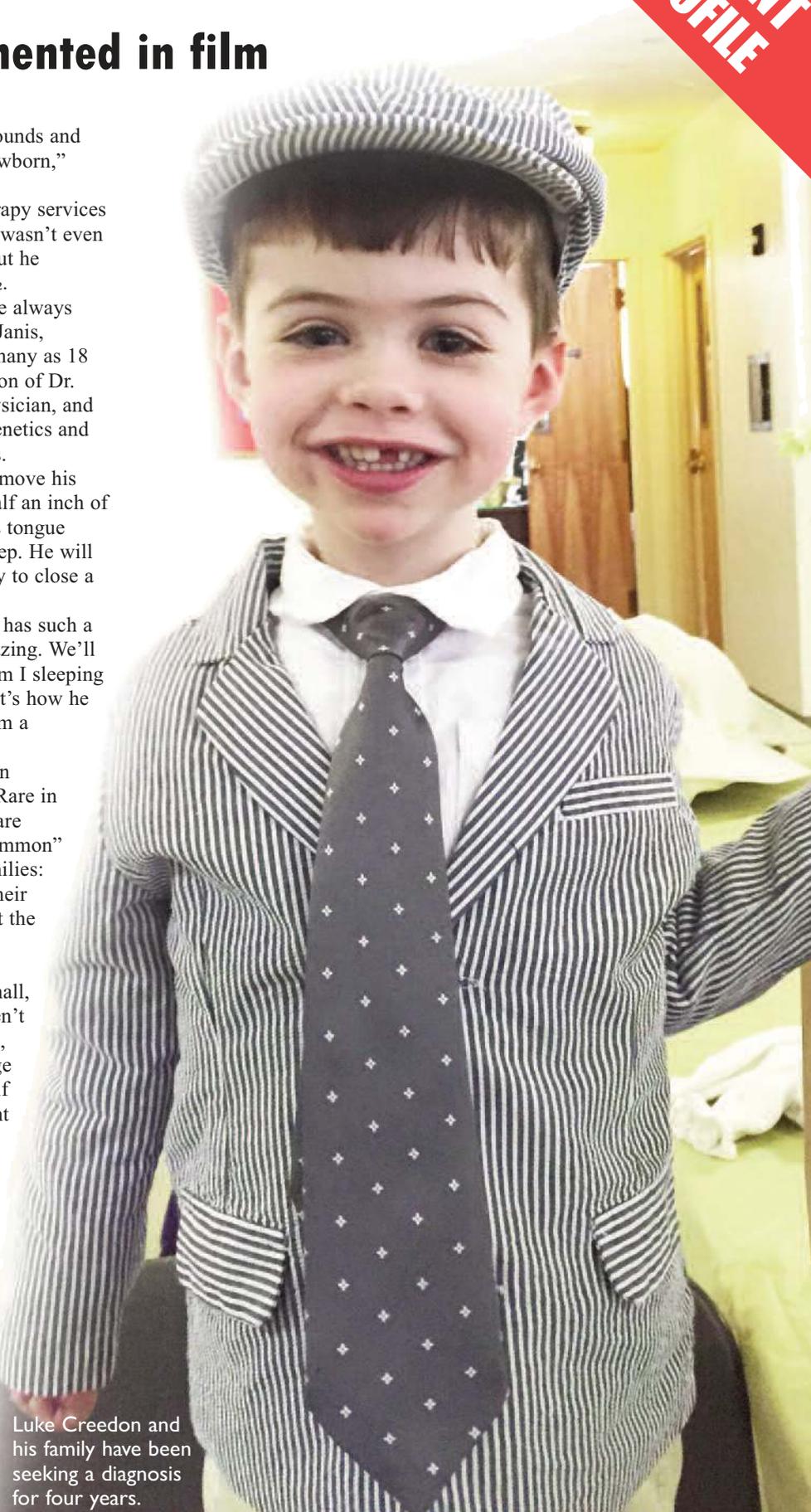
The Creedons' story is featured in Cambridge BioMarketing's film, "Rare in Common." Produced in time for Rare Disease Day this year, "Rare in Common" follows the experiences of rare families: their struggles, their strength and their hope for the future as they confront the challenges of living with a rare disease.

"Because the population is so small, often the voices of rare patients aren't loud enough," said Alisa Shakarian, creative director of art at Cambridge BioMarketing. "We thought, what if we brought them together to present a bigger story, with a louder voice. This is their forum to showcase their unique stories."

Film producers spent time with each of the families, capturing their lives and medical journeys—starting with the path to diagnosis and transitioning to stages of treatment, advocacy and caregiving.

"These people are so inspiring," said Shakarian.

See **PATIENT** Page 7



Luke Creedon and his family have been seeking a diagnosis for four years.

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PROFILE**