

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

## AGENDA

**1:00 p.m.**

**Registration & Networking**

**1:30 p.m.**

**Welcome Remarks**

James T. Brett, President & CEO

The New England Council

**Keynote Introduction**

Scott Weintraub, Senior Vice President, US Business  
Alexion, AstraZeneca Rare Disease

**1:45 p.m.**

**Keynote Remarks and Q&A**

U.S. Representative Jake Auchincloss (D-MA)

**2:30 p.m.**

**Panel Discussion**

*Moderator:*

Del Lebel, Head of US Government Affairs and Policy  
Alexion, AstraZeneca Rare Disease

*Panelists:*

- Irene Abrams, Vice President, Technology Development and New Ventures, Boston Children's Hospital
- Duane Clark, Head of US Rare Disease, Sanofi
- Betsy O'Neill, Vice President, External Research & Development, Rare Disease, Amgen
- Heidi Ross, MPH, Vice President, Policy and Regulatory Affairs National Organization for Rare Disorders
- Craig Wilkinson, Sr. Director, US Medical Affairs, Novocure

**3:30 p.m.**

**Program concludes**



Join the conversation @NECouncil and use the hashtag #NEInnovates

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

## SPEAKER & PANEL BIOGRAPHIES

### Introductory Remarks

#### **Scott Weintraub**

**Senior Vice President, United States Business**

**Alexion, AstraZeneca Rare Disease**

Scott has country operating responsibility for the United States Rare Disease Business, leading an organization of over 1,000 colleagues across sales, medical, market access, marketing, operations, regulatory affairs, finance, human resources, and patient services. In this role, Scott is accountable for the reputation, customer satisfaction, revenue, and profit of the United States Rare Disease Business. Additionally, Scott serves as the site lead for our Rare Disease Headquarters in Boston, MA.

Prior to his current role, Scott was SVP of the US Commercial Business and VP of Global Marketing and Strategy. He first joined Alexion in 2019 as VP, Head of Neurology & Ophthalmology TAs. Scott has over 20 years of commercial experience in the biopharmaceutical industry, including strategic product assessment, brand positioning, commercial life cycle management, business development, analytics, sales, and marketing.

Scott is a skilled and thoughtful company spokesperson and regularly interfaces with board members, media, customers, patient advocacy groups and investors on behalf of the organization. Scott has also been a board member for the Alexion Political Action Committee (PAC) since 2023.

Scott holds a BS in Finance and Marketing from Florida State University and an MBA in Health Administration and Policy from the University of Miami. Today, he resides in Boston, MA.

### Keynote Remarks

#### **U.S. Representative Jake Auchincloss (D-MA)**

Congressman Jake Auchincloss is serving his second term representing the Massachusetts Fourth. In addition to his work on the committees for Transportation & Infrastructure and the Select Committee on Strategic Competition Between the United States and China, his areas of focus include healthcare, clean energy, gun violence, and building a strong middle class.

Jake was born and raised in Newton, Massachusetts, the son of a surgeon and a scientist. They showed him the value of curiosity and hard work. From the moment he could read, Jake loved American history.



Join the conversation @NECouncil and use the hashtag #NEInnovates

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

After graduating from Harvard College, Jake joined the Marines. He commanded infantry in Afghanistan and special operations in Panama.

Upon returning home, Jake continued his service as a three-term city councilor in Newton. While working at City Hall on nights and weekends, Jake built a career in business, running product development at both a Fortune 100 insurance company and a cybersecurity startup. He has degrees in Economics and Finance from Harvard University and MIT Sloan.

Today, Jake lives in Newton with his wife, Michelle, and their children, Teddy, Grace, and Audrey (along with their Labrador Retriever, Donut).

Read Rep. Auchincloss' recent Boston Globe Op-Ed, [Congress should commit to US biotechnology leadership](#).

## **Panel Moderator**

**Del Lebel**

**Head of US Government Affairs and Policy**

**Alexion, AstraZeneca Rare Disease**

Del Lebel is the Head of US Government Affairs and Policy at Alexion, AstraZeneca Rare Disease. In this position, he leads Alexion's government relations activities and provides strategic oversight to execute Alexion's legislative and regulatory policies and objectives involving federal and state government affairs. Del is a member of Alexion's United States Leadership Team and works with Alexion's Executive Team to drive the organization's strategic priorities.

Throughout his twenty-five-year career in the life sciences industry, he has gained extensive experience and held leadership roles that span government affairs, healthcare policy, reimbursement, and strategic alliance development with industry-leading global biopharma corporations.

Del is involved with numerous coalitions that bring together rare disease experts, advocates, and industry leaders to identify and advocate for solutions to alleviate access burdens for the rare disease community. He is on the Board of Directors and sits on the Executive Committee for the Rare Disease Company Coalition.



Join the conversation @NECouncil and use the hashtag #NEInnovates

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

## Panelists

### **Irene Abrams**

**Vice President, Technology Development and New Ventures  
Boston Children's Hospital**

Irene is the Vice President of Technology Development and New Ventures at Boston Children's Hospital, leading the Technology & Innovation Development Office (TIDO). TIDO is responsible for commercializing discoveries and innovations developed by researchers and clinicians at Boston Children's Hospital. Irene is also the Managing Director of the Technology Development Fund.

Prior to joining Boston Children's, Irene was an Executive Director at Partners Healthcare Innovation, responsible for commercializing technology from Massachusetts General Hospital. Before joining Partners, Irene was the Associate Provost for Innovation at Brandeis University and founded the Brandeis Virtual Incubator. Prior to joining Brandeis, Irene was a Senior Technology Licensing Officer at M.I.T., where she focused on licensing biotech inventions for M.I.T., the Whitehead Institute and the Broad Institute.

Irene did her undergraduate work at the University of Pennsylvania and her graduate work at the Johns Hopkins University and M.I.T. Irene is the past President of the Massachusetts Association of Technology Transfer Offices, the founder of T3, a networking organization for technology licensing offices from small New England research institutions, and a former Vice President of the Associate of University Technology Managers.

### **Duane Clark**

**Head of the US Rare Disease Business  
Sanofi**

R. Duane Clark is General Manager, Rare Disease, Sanofi.

Duane is a 30+year leader in the healthcare industry with a professional and vocal passion for the rare disease community. Over his career he has held executive leadership positions in General Management, Sales, Marketing, Commercial Operations, Project Management, Consulting and a CRO. He has led high performing organizations in the US, EU, and Canada.

Duane's positive winning is forward approach fuels his one team, common goals, single mission mindset working equitably across all races, genders, disabilities, and backgrounds.

Duane participates in family activities, triathlons, scuba diving, motorcycle riding, cooking, beach relaxation and prayer to maintain balance. He gives back as an advocate for the homeless, the covington life sciences project, and relentless talent development fueling the next generation.



Join the conversation @NECouncil and use the hashtag #NEInnovates

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

## **Betsy O'Neill**

**Vice President, External Research & Development, Rare Disease  
Amgen**

Betsy is a scientifically trained business development executive and has held positions with life science firms ranging from VC incubation through large cap biotech. In her current role at Amgen, she leads External R&D for Rare Disease, with the goal of bringing new rare disease drug candidates into Amgen's pipeline. Betsy joined Amgen in 2023, via Amgen's acquisition of Horizon Therapeutics, where she also led in-licensing efforts for rare diseases. Prior to Horizon, she held similar positions at BioMarin, Elan Pharmaceuticals and Tularik. She has closed numerous deals in her career, ranging from preclinical academic licenses through public company M&A. With both an MBA and a Biology PhD from UC Berkeley, and a Biology undergrad degree from MIT, Betsy is well positioned for both the business and scientific aspects of her roles.

## **Heidi Ross**

**Vice President, Policy and Regulatory Affairs  
National Organization for Rare Disorders**

Heidi Ross is the Vice President of Policy and Regulatory Affairs at the National Organization for Rare Disorders (NORD). Heidi has built a career out of her passion for domestic and global health policy, and she joined NORD in January 2020.

Prior to joining NORD, Heidi worked for nearly five years at Malaria No More, where she worked as the Director of US Policy and Advocacy, and Africa Programs. Prior to her time at Malaria No More, Heidi worked on Capitol Hill for nearly eight years in both the House of Representatives and the Senate.

Heidi holds a Bachelor of Science in Psychology from Northern Arizona University and a Master of Public Health with a focus on health policy from the George Washington University.

## **Craig Wilkinson**

**Sr. Director, US Medical Affairs  
Novocure**

Craig is a radiation oncologist who joined Novocure in 2022 and is the Senior Medical Director, Head of Medical Affairs for the US. Craig leads teams in CNS and Thoracic indications. Craig received his MD at the University of Miami School of Medicine and completed his residency in radiation oncology at the Sylvester Cancer Center at the University of Miami School of Medicine. He then went on to join a large private practice based in Atlanta, GA. Craig has over 17 years of radiation oncology practice experience and has been prescribing TTFIELDS therapy to his glioblastoma patients since 2015.



Join the conversation @NECouncil and use the hashtag #NEInnovates

# New England Innovates: Tackling Rare Diseases

THE  
NEW ENGLAND  
COUNCIL

Featuring

U.S. Representative Jake Auchincloss

April 23, 2024 - Seaport Hotel

## THANK YOU TO OUR SPONSOR

The logo for Alexion, featuring the word "ALEXION" in a bold, blue, sans-serif font. A blue arc curves over the letters "A" and "L". A small red triangle is positioned above the letter "X". A registered trademark symbol (®) is located to the right of the word "ALEXION".  
AstraZeneca Rare Disease



Join the conversation @NECouncil and use the hashtag #NEInnovates