**CONFERENCE DRAFT AGENDA**

**Conference Facilitator:**
**Mark Trusheim, MSc, Strategic Director, NEWDIGS**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session/Remarks</th>
<th>Speaker/Panelists</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30</td>
<td>Welcome</td>
<td>David Goldston, PhD, Director, MIT Washington D.C. Office</td>
</tr>
<tr>
<td></td>
<td>Opening Remarks</td>
<td>Gigi Hirsch, MD, Executive Director, Center for Biomedical Innovation and Program Director, NEWDIGS</td>
</tr>
</tbody>
</table>

**PART 1: Understanding Curative and Durable Therapies**

9:40 **Panel Session**

*Why Are We Here? The Science, Patients and System Readiness for Curative Therapies*

This panel will bring together the science, patient and systems perspectives on the advent of durable/curative therapies. Where can the science go from here? How does it impact the hopes, dreams and daily lives of patients and what is the state of operational readiness for the system to deal with this paradigm shift in healthcare.

**Moderator:**
**Janet Lynch Lambert, MBA, CEO, Alliance for Regenerative Medicine (ARM)**

**Panelists:**
- **Science**
  - Usman “Oz” Azam, MD, President & CEO, Tmunity Therapeutics
- **Patients**
  - Marc Boutin, JD, CEO, National Health Council
  - Anish Goel, PhD, Beta-Thalassemia patient
- **System**
  - Murray Ross, PhD, Vice President, Kaiser Permanente

*The conference agenda is subject to change*
10:20  **Cell & Gene Therapies**

**Drug Development Pipeline**

**Colin M. Young**, PhD, Director, Drug Development Pipeline Research, MIT FoCUS Project

---

10:40  **BREAKE**

---

**PART 2: Challenges to Accessibility**

10:55  **Panel Session**

**Financial Challenges Imposed by Curative Therapies: Real or Imagined**

Panelists will react to the previous panel session on the Science, Patient and Systems dynamics as they relate to the advent of cell and gene therapy rollouts and what they meant to the future of healthcare, as well as predications of the drug development pipeline. Panelists will discuss the many challenges beyond price, presented by the durable/curative therapies from each stakeholder perspective.

**Moderator:**

**Steve Usdin**, Senior Editor (Washington), Head Policy & Regulation, BioCentury and BioCentury Innovations

**Panelists:**

**Provider**

- **Joseph Alvarnas**, MD, Vice President, Government Affairs & Senior Medical Director, Employer Strategy, City of Hope

**Patient Advocacy**

- **Tim Brent**, Senior Director, Business Development, National Hemophilia Foundation

**Self-Insured Employer**

- **Robert Galvin**, MD, CEO, Equity Healthcare *(former Executive Director, Health Services & Chief Medical Officer, General Electric)*

**Public Payer**

- **Darin Gordon**, Founding Partner, Speire Healthcare Strategies, *(former Director, Tennessee Medicaid program-TennCare)*

**National Payer**

- **TBD**

**Government/Regulatory**

- **John O’Brien**, PharmD, MPH, Senior Advisor for Drug Pricing Reform, Health and Human Services *(Invited)*
12:35 **Keynote Speaker**
How medicine is changing, what it means to improved health and why there is a need to create alternative financing mechanisms.

**Introduction:**
Jonathan Gruber, PhD, Ford Professor of Economics, MIT and Director, Health Care Program, National Bureau of Economic Research

**Keynote:**
Senator Bill Cassidy (R) U.S. Senator for Louisiana

1:00 **Panel Session**
**The FoCUS Project: Precision Financing Solutions**
Go behind the scenes with this panel on the creation of financing and reimbursement solutions to the myriad of challenges brought by the upfront cost of the durable/curative therapies. Stakeholder representatives will highlight and review the case studies utilized in the development of precision financing ideas.

**Moderator:**
Mark Trusheim, MSc, Strategic Director, NEWDIGS

**Panelists:**
*FoCUS Project Development & Goals*
- **Edmund Pezalla,** MD, MPH, CEO Enlightenment Bio-consulting *(former Vice President, National Medical Director, Pharmaceutical Policy and Strategy, Aetna)*

*Blood Disorders Case study/Performance-based Annuities*
- **Chuck Bucklar,** Group Vice President, Commercial Operations, North America, BioMarin Pharmaceutical Inc.

*CAR-T Case Study/Milestone-based Rebates*
- **Krishna Komanduri,** MD, Kalish Family Chair in Stem Cell Transplantation; Professor of Medicine and Associate Director, Clinical Innovation, Sylvester Comprehensive Cancer Center, University of Miami Miller School of Medicine

*Ultra-Orphans Case Study/Orphan Reinsurer Benefit Manager*
- **Michael Ciarametaro,** MBA, Vice President Research, National Pharmaceutical Council
This panel will describe the pilots FoCUS is designing, including plans for a Massachusetts pilot on performance-based annuities with commercial payers, and milestone-based contracts with public payers.

**Moderator:**

**Rena Conti**, PhD, Associate Professor, Markets, Public Policy, and Law; Associate Research Director, Biopharma and Public Policy, Institute for Health System Innovation and Policy, Boston University Questrom School of Business

**Panelists:**

*Performance-based Annuities with Commercial Payers*

- **Lovena Chaput**, Vice President, Managed Markets & Reimbursement, AveXis
- **Michael Sherman**, MD, MBA, MS, Chief Medical Officer and Senior Vice President, Harvard Pilgrim Health Care

*Milestone-based Contracts with Public Payers*

- **John Glasspool** - Board Member, DalCor Pharmaceuticals, Senior Advisor, FoCUS Project
- **Jeff Myers** - EVP Strategy and External Relations - CareSource (former president and CEO of Medicaid Health Plans of America (MHPA))
2:30 **Identifying Opportunities for Enabling Precision Financing**

All precision financing solutions, including those proposed by the FoCUS Consortium, will require improvements to existing financial systems. This panel will explore what those challenges are, how they might be overcome and what you can do to aid in this endeavor.

**Moderator:**
**Gregory Daniel,** PhD, MPH, Deputy Director, Policy, Duke – Robert J. Margolis MD, Center for Health Policy & Clinical Professor, Fuqua School of Business

**Panelists:**

*Private Payer, PBM and Medicare*
- **Kim Caldwell,** RPh, Principal, Texas Star Healthcare Consulting, LLC *(former Division Director, Medicare Drug Benefit Group, CMS; Vice President of Pharmacy Professional Affairs & Comprehensive Health, Humana Inc.)*

*Regulatory*
- **Brian Carey,** Partner, Foley-Hoag LLP

*Stop-Loss/Reinsurance*
- **Mehb Khoja,** FSA, MAAA, President, Medical Risk Managers Inc. (MRM)

*Patient Advocacy*
- **Peter Saltonstall,** President and CEO, National Organization for Rare Diseases (NORD)

3:20 **Keynote Speaker**

The current climate on Capitol Hill around payment reform and opportunities for innovation in pricing arrangements.

**Introduction**
**Krystyn Van Vliet,** PhD, Associate Provost and Professor of Materials Science & Engineering & Biological Engineering, MIT

**Senator Sheldon Whitehouse** (D) – U.S. Senator for Rhode Island

3:40 **Wrap Up – Audience Engagement**

**Moderator:**
**Mark Trusheim,** MSc, Strategic Director, NEWDIGS

4:00 **Adjourn**