# **SEPTEMBER 15–16, 2014 ePatient EXI** WYNDHAM PHILADELPHIA HISTORIC DISTRICT HOTEL Connections/2014

Multiple Stakeholders Showcasing Industry's Best Practices to Connect and Strengthen Relations with ePatients



# OUR DISTINGUISHED FACULTY INCLUDE:

Scott Benner **DIABETES HEALTH** ACTIVIST V



Anne Marie Ciccarella **BREAST CANCER HEALTH ACTIVIST** 



Lisa R. Courtade MERCK & COMPANY V



Chris Field **ROCHE** DIAGNOSTIC



John Hixson **DEPARTMENT OF VETERAN AFFAIRS** 



Kathy Hutchens SHARP REES-STEALY MEDICAL CENTERS





**Emily** Kramer-Golinkoff **CYSTIC FIBROSIS HEALTH ACTIVIST** 



Jaimie Mattson **MEDTRONIC** 



Craig Ostroff A **OTSUKA PHARMACEUTICALS** 



Marjorie Reedy A TELERXTEAM AT MERCK & **COMPANY** 



Sarah Spielvogel ▲ NOVO NORDISK A/S



Mark Wiley A **PHARMACEUTICALS** 

# Top 5 Reasons to Attend

- Through case studies, gain a better understanding of how pharmaceutical companies use social media platforms and digital tools to connect with online patient communities
- Discuss the evolution of the ePatient and it's role in generating tailored content applicable in healthcare
- Explore the use of third party contributors and multichannel engagements to strengthen stakeholder relationships with online patient communities
- Learn about how multiple stakeholders interact with ePatients and the impact on health outcomes and patient engagement
- **Examine** the challenges that industry and ePatients face when trying to understand the regulatory landscape of social media

### **Topics Covered:**

- > The impact of digital engagements on healthcare providers and patients
- >> Vehicles used by pharma and healthcare providers to engage with ePatients
- Content marketing to reach ePatients
- >> Connecting with ePatients for Medical Device
- > Social Media Regulatory /FDA Guidance on Social Media

### Supporting Sponsors:







# ePatient Connections/2014

Dear Colleague,

It is hard to describe and define patients in the modern world; patients are constantly evolving and the increased use of technology and digital engagements in the healthcare landscape enables them to take an active role in their healthcare like never before, transforming their interactions with doctors, caregivers and drug manufacturers. This active role is generating more educated, hands-on digital patients that are in turn creating online communities and influencing research through the constant production of healthcare data.

Multiple stakeholders in the healthcare, pharmaceutical, medical device and biotechnology fields have shifted their attention to these online communities and are looking for effective ways to connect with them. Nevertheless, effectively achieving that connection requires a deep understanding of their uniqueness, needs and expectations. Nevertheless, effectively achieving that connection requires a deep understanding of their uniqueness, needs and expectations. The ePatient Connections 2014 summit, dives into the ePatient ecosystem and explores the different facets of patient engagement.

This event is designed for pharmaceutical, biotechnology, medical device companies and healthcare providers to understand how to effectively communicate and connect with ePatients and growing ePatient communities. Additionally, through multiple case studies and panel sessions the event gives a broad perspective on how different patient groups use of social media platforms and digital tools, and creates an environment in which the audience can see how multiple stakeholders interact with each other and the major challenges they face when doing so.

I look forward to meeting you in September!

Sincerely,

## Katerina Leon

Katerina Leon / @ePatCon2014 Conference Director, ePatient Connections kleon@exlpharma.com

### **Booking Details:**



Wyndham Philadelphia Historic District 400 Arch Street Philadelphia, PA 19106

To make reservations please call 1-877-999-3223 and request the negotiated rate for ExL's September Meetings.

The group rate is available until August 25, 2014. Please book your room early as rooms available at this rate are limited.

# This **conference** is designed for:

**Life Science Professionals** (Pharma, biotech, medical devices, physicians, payers) with responsibilities in the following areas:

- Marketing / eMarketing
- Digital Strategy / Marketing
- Social Media / Media Strategy
- Patient Recruitment / Patient engagement
- Medical Communications
- Medical Education
- Physician/HCP Marketing
- Product / Brand Management
- Multi Channel Marketing
- Information Technology
- Regulatory and Compliance
- Patient Adherence
- Patient Advocacy

#### ePatients:

- Patients and their online communities
- Caregivers

# This **conference** is also of interest to service providers including:

- Public Relations and Advertising Agencies
- Marketing and Interactive Marketing Agencies
- Consultants
- Technology Vendors in the Mobile Health space

# INTERESTED IN SPONSORSHIP & EXHIBITION OPPORTUNITIES?

Do you want to spread the word about your organization's solutions and services to potential clients who attend this event? Take advantage of the opportunity to exhibit, present an educational session, host a networking event, or distribute promotional items to attendees. ExL works closely with you to customize a package that suits all of your needs.

To learn more about these opportunities, contact Sean Blank, Business Development Manager at 917-258-5154 or sblank@exlpharma.com

# **MEDIA PARTNERS:**

















# Monday, September 15th, 2014

> DAY ONE

8:00 Registration Opens & Continental Breakfast 8:45

Featured kick-off talk

9:30

Co-chairperson's Opening Remarks

AnneMarie Ciccarella, Breast Cancer Health Activist, creator of the blog 'CHEMOBRAIN... IN THE FOG', @CHEMOBRAINFOG

Lisa R.Courtade, Executive Director, Global Market Research Excellence, MERCK & COMPANY, @LISACOURTADE

#### 9:00 **Authentic Humanity: Why it Matters Above all Else**

- Understand the responsibility that comes with becoming part of a patient community
- Explore ways to identify content creators within your organization that will add to the collective consciousness of the community
- . Why you must stop thinking of the text that you share as 'content' to trusted, supportive and relied upon source

Scott Benner, Diabetes Health Activist, author of 'LIFE IS SHORT, LAUNDRY IS ETERNAL', @ARDENSDAY

### Retain and Engage Patients in a Digital World

- Understand the challenges in acquisition and retention of patients and create meaningful online support
- Utilize the point of care as a resource to understand content development vs. content curating
- · Reciprocity, have you thanked your customers lately? Chris Field, Associate Marketing Manager, Patient /Consumer Marketing, ROCHE DIABETES CARE

#### 10:00 Digital Channels and their Role in Research and Development as Effective Tools to Improve Clinical Trial Patient Enrollment

- The use of digital and social media platforms to increase study awareness and patient participation in clinical trials
- Online trends in patient's use of digital and social media platforms and potential opportunities in clinical trial recruitment

Melody Toorneman, Director Digital Practices, Global Medical Platforms and Capabilities, GLAXOSMITHKLINE

10:30 **Networking Break** 

#### 11:00 **Explore the Interactions Between Online Communities and Pharmaceutical Companies**

- Learn how through educational efforts pharmaceutical companies have approached patient communities
- · Discover patient's feedback when being approached by pharmaceutical companies and other healthcare providers
- · Understand why for many devastating diseases like cystic fibrosis, it is essential to evolve strong partnerships with multiple stakeholders

Jeanne Barnett, Founder, CYSTICFIBROSIS.COM,

### **Engage Patients in Their Healthcare Decision-Making by** 11:30

- · Learn how the internet is facilitating patients to take charge of their
- Explore how the pharmaceutical industry is responding to the

Marjorie Reedy, Director, Market Research Center of Excellence, MERCK & CO.

#### 12:00 Learn About Patient-Generated Data and how this Content can Better Utilized and Valued

- · Learn about the current methods for collecting health-related data through online communities and at-home monitoring systems
- Discuss how current online data collection platforms are improving doctor-patient communications and care plans

• Examine the healthcare system's incentive structure and explore industry opportunities to capitalize and invest in new approaches to patient-generated health content

John Hixson, Assistant Professor of Clinical Neurology, UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, Clinical Lead for Patient-Facing Technologies, DEPARTMENT OF VETERANS AFFAIRS, @POEMSTUDY

12:30

### The use of a Nurse's Online Portal to Turn Multiple Myeloma **Patients into Empowered ePatients**

- Learn how Millennium Pharmaceuticals and Klick Health are helping nurses turn multiple myeloma patients into empowered ePatients
- Discuss the impact on patient engagement of Millennium Pharmaceuticals' nurses portal on the VELCADE website
- · Explore the effect of the VELCADE nurses portal in setting expectations for nurses and patients through the different stages of the treatment of multiple myeloma

Simon Greer, Sr. Digital Strategist, KLICK HEALTH

#### 2:00 **Understand Social Media's Impact on patient Communities** and Ways to Develop Valuable Relationships with ePatients

- Explore the use of different social media platforms by patient and caregiver communities according to therapeutic category
- Understand what the social media health community wants from
- Discuss best practices to understand the unique needs and expectations of patients in order to deliver high-value initiatives and community relationships

Moderator: Melissa Barnhart, VP, WEGO Health - @MBFOOTPRINTS Panelists:

Jodi Seidler, Osteoporosis Health Activist, creator of 'THE HIPSTER CLUB,' @BOOMERBABE1

Stacie Van Brandenburg, Lyme Disease Health Activist, creator of 'FIGHT LYME,' @FIGHTLYME

Kelly Conway, Rheumatoid Arthritis Health Activist, co-founder of the INTERNATIONAL FOUNDATION FOR AUTOIMMUNE ARTHRITIS, @LOLABELLAQUIN AND/OR @IFAARTHRITIS

Catherine Price, Diabetes Health Activist, health & nutrition writer, @CATHERINE PRICE

### The Importance of Patient Advocates and Their Role to Support, Engage and Connect with Multiple Stakeholders

- · Learn about patient ambassadors and their role as leaders to serve the needs of consumers at the disease state point
- · Explore the use of patient ambassadors to connect brands to other patients, healthcare providers and policy makers
- Examine Novo Nordisk's best practices to connect with multiple

Sarah Spielvogel, Senior Manager, Product Communications at NOVO **NORDISK A/S** 

3:15 Networking Break

# "e-Man!" -Successful Strategies for Engaging Men and their

- · Learn about consumer research tools to better understand the male market in the digital space
- Understand the role that the type of disease and demographics play in the way men engage digitally
- · Understand ways to influence behavioral searches and provide ROI options based on the type of patient

Mark Wiley, Market Research Manager at AUXILIUM

**PHARMACEUTICALS** 



1:30

·· Case Study

ePatient Panel

2:45

Case Study

3:45

Case Study

@JEANNEBARNETT Chris Baldwin, CEO, CYSTICFIBROSIS.COM **Utilizing Digital Resources** health • Understand the impact of the internet in driving better patient increased reliance on digital health

Conversation

# Monday, September 15th, 2014 continued

**Group Discussion** 



#### 4:15 **Examine How Multiple Stakeholders Interact with ePatients** and the Impact on Health Outcomes and Patient Engagement

- Understand the conversation between pharma, patients, payers doctors, and government
- · Learn about the different challenges faced by multiple stakeholders when connecting with ePatients
- · Explore ways to improve existing interactions between epatients and stakeholders

Moderator: Craig deLarge, Global Leader, Multichannel Marketing Strategy & Innovation at MERCK & COMPANY, @CADELARGE

Baber Ghauri, Chief Medical Information Officer, ST. MARY MEDICAL CENTER, @DRBABERGHAURI

Emily Kramer-Golinkoff, Cystic Fibrosis Health Activist, Co-founder of EMILY'S ENTOURAGE, @EMILYKG1

Jonathan Cho, Chief, Communications Technology Branch at NATIONAL CANCER INSTITUTE, @CHOSPLACE

5:00 Conclusion of Day One

# > DAY TWO

# **Tuesday, September 16th, 2014**

8:00 Registration Opens & Continental Breakfast Co-chairperson's Opening Remarks

**Group Discussion** 

9:00

AnneMarie Ciccarella, Breast Cancer Health Activist, creator of the blog 'CHEMOBRAIN... IN THE FOG', @CHEMOBRAINFOG

> Lisa R.Courtade, Executive Director, Global Market Research Excellence, MERCK & COMPANY, @LISACOURTADE

#### 9:15 **Build the Experience - Connecting with ePatients for Medical Device Organizations**

- Trends, interactions and challenges for medical device organizations when connecting with ePatients
- · Learn about best practices for starting the engagement process with
  - Social media/ digital engagement in the medical device industry pros/cons
  - Tools/media for device patient education
- · Social media as a tool for patient's impact on product development Jaimie Mattson, Sr. Marketing Manager - Cardiac Connected Care at MEDTRONIC, @MATTSJ1

#### 9:45 **Utilize Content Marketing as a Way to Deliver Relevant Disease Information, Build Brand Awareness and Increase Patient Lovalty**

- · Build a relevant story amongst unique target populations. Balance effective channel integration and tactical pull-through
- · Coordinating feedback loops to update content and personalize communications
- Understand the ROI when engaging with patients through nonpromotional education

Peter Chiappano, Manager, Account Planning and Strategy Advertising & Marketing Services, Worldwide Commercial Operations, BRISTOL **MYERS-SQUIBB** 

10:15 Networking Break

### 10:45 Shire's Bravecommunity for Rare Disease Education and

- · Learn about Shire's educational resource to provide high quality scientific disease information for patients/caregivers and healthcare
- Understand the impact and importance of the different available educational resources in online patient communities

Nicole Rojas, Global Digital Communications Director, SHIRE **PHARMACEUTICALS** 

#### 11:15 **Collaborative Outsourcing through Third Parties to Strengthen** Stakeholder Relationships with Online Patient Communities

- Understand why partnering with third-party contributors is central to infiltrate niche epatient communities and gather important disease
- Discuss what collaboration model among agencies, vendors, clients, and patient communities works best to achieve better health outcomes

· Learn about the role of patient leaders in creating brand awareness and increasing brand loyalty

Phil Baumann, Member of the Advisory board at the MAYO CLINIC CENTER FOR SOCIAL MEDIA, @PHILBAUMANN

#### Is the Guest of Honor at Your Table? 11:45

- Learn why a qualified patient voice at the table is an invaluable and underutilized tool
- How can each sector identify which patients to invite to their table?
- The potential for tremendous savings in both cost and time by involving patients at all stages across the continuum of care, bench

AnneMarie Ciccarella, Breast Cancer Health Activist, creator of the blog 'CHEMOBRAIN... IN THE FOG', @CHEMOBRAINFOG

- 12:15 Luncheon
- 1:15 The Importance of Both Industry and ePatient Understanding the Regulatory Landscape of Social Media
  - · Learn how to successfully navigate the regulatory landscape of social
  - Discuss the FDA's latest draft guidance on social media
  - · Messaging to patients on the regulatory limitations of social media faced by pharma

Craig Ostroff, Senior Director, Global Regulatory Affairs, OTSUKA **PHARMACEUTICALS** 

#### 1:45 The Use Of Social Media Platforms to Connect, Equip, **Engage and Empower ePatients**

- · Understand patient's ROI when engaging in social media and ways to use this to your benefit
- · Learn about the role of caregivers as active social media participants and the impact in patient's health
- Learn about the pharmaceutical social media channels that are in place to receive feedback from patients

Moderator: Lisa R. Courtade, Executive Director Global Market Research Excellence, MERCK & COMPANY, @LISACOURTADE

### Panelists:

Frank Garufi, IBD Health Activist, creator of 'THE CROHN'S COLITIS EFFECT,' @CROHNSEFFECT

Leslie Rott PhD, Lupus and Rheumatoid Arthritis Health Activist, creator of the blog 'GETTING CLOSER TO MYSELF', @LESLIEROTT

Tahirah Austin, Sickle Cell Disease Health Activist, @TAHIRAHAKILA

Nicole McLean, Breast Cancer Health Activist, creator of blog 'MY FABULOUS BOOBIES', @NIC MCLEAN

Baber Ghauri, Chief Medical Information Officer, ST. MARY MEDICAL **CENTER** 

Alison Woo, Director, Social Media, BRISTOL-MYERS SQUIBB

Panel

# Tuesday, September 16th, 2014 continued



#### 2:30 Networking Break

### 2:45 Multi-Channel Engagement Strategies for the Connected

- · Learn how Sharp Rees-Stealy Medical Centers, utilizes a variety of communication channels to attract, retain and engage patients
- Explore the most effective digital engagement tools and strategies to educate and inform patients, improve compliance and enhance the doctor-patient relationship
- · Hear about the barriers to connect with patients and learn what's on the horizon to improve their health across a variety of communication channels

Kathy Hutchens, Vice President, Business Development and Patient Engagement at SHARP REES-STEALY MEDICAL CENTERS

#### 3:15 **Evolution of Digital Health Communications at the National Cancer Institute**

- · Learn how a multi-channel strategy enhances the effectiveness of digital content in public health.
- · Highlights: Digital Strategy, Content Strategy, Enterprise Systems, and Community Engagement

• The Art of C.O.P.E. (Create Once and Publish Everywhere) Jonathan Cho Chief, Communications Technology Branch at NATIONAL CANCER INSTITUTE, @CHOSPLACE

Lakshmi Grama, Senior Digital Content Strategist NATIONAL CANCER INSTITUTE, @LGRAMA

4:00 Closing Remarks

#### Epatient Meet-up Putting the "e" in ePatient - Meet-Up and 4:15 **Round Table Session**

This 90-minute Meet-up will feature a rich discussion about the needs and key components of ePatient communities and how industry can better support healthcare decision making and improve health outcomes.

This ePatient session will include:

- Examples of patient support programs from industry and non-profit
- Roundtable Meet-up exercises
- The creation of ePatient-Industry guidelines that Empower, Engage, Equip, and Enable

# Registration Information



**ONSITE PRICING:** 

Conference



\$1.595

registration@exlpharma.com



## Registration Fees **FOR-PROFIT PRICING EARLY BIRD PRICING:** Register Before Friday, August 1st, 2014 \$1,795 Conference STANDARD PRICING: Conference \$1,995 **ONSITE PRICING:** \$2,095 Conference **NON-PROFIT PRICING\* EARLY BIRD PRICING:** Register Before Friday, August 1st, 2014 Conference \$1,295 STANDARD PRICING: Conference \$1,495

\*Nonprofit rate is reserved for full time employees of an accredited nonprofit organization. This rate cannot be combined with group discounts

Save 25% per person when registering four For every three simultaneous registrations from your company, you will receive a fourth complimentary registration to the program (must register 4 at one time) this is a savings of 25% per person.

Save 15% per person when registering three Can only send three? You can still save 15% off of every registration. To find out more on how you can take advantage of these group discounts, please call 866-207-6528. Terms & Conditions By registering for an ExL Events, Inc. ("ExL Pharma") event, you agree to the following set of terms and conditions listed below:

Registration Fee: The fee includes the conference, all program materials, and designated continental breakfasts, lunches and refreshments. Payment: Make checks payable to ExL Events, Inc. and write code C491 on your check. You may also use Visa, MasterCard, Discover or American Express. Payments must be received in full prior to the commencement of the conference. Any discount applied cannot be combined with any other offer, and must be paid in full at the time of order. Parties must be employed by the same organization and register simultaneously to realize group discount pricing options. Group discounts available to individuals must be registered simultaneously and employed by the same organization.

### **Cancellation and Refund Policy**

If you need to cancel your registration for an upcoming ExL event, please note the following policies derived from the Start Date of the event:

- Four weeks or more: A full refund (minus a \$295 processing fee) or a voucher to another ExL event valid for 18 months from the voucher issue date.
- Less than four weeks: A voucher to another ExL event valid for 18 months from the voucher issue

If you cancel at any time after receiving the conference documentation, the voucher issued will be \$395 less

Substitution Charges: There will be an administrative charge of \$300 to substitute, exchange and/or replace attendee badges with a colleague occurring within five business days of the conference.

ExL Pharma reserves the right to cancel any conference it deems necessary and will not be responsible for airfare, hotel or any other costs incurred by registrants.

ExL Pharma's liability is limited to the conference registration fee in the event of a cancellation and does not include changes in program date, content, speakers, or venue.

· The opinions of ExL speakers do not necessarily reflect those of the companies they represent, nor ExL Events, Inc.

Please Note: Speakers and agenda are subject to change without notice. In the event of a speaker cancellation, significant effort to find a suitable replacement will be made.

The content in ExL slide presentations, including news, data, advertisements and other information, is provided by ExL Events, Inc.'s ("ExL's") designated speakers and is designed for informational purposes for its attendees, and is NOT INTENDED for purposes of copywriting, nor redistribution to other outlets without the express written permission of ExL's designated speaking parties. Neither ExL, nor its content providers and/or speakers and attendees shall be liable for any errors, inaccuracies or delays in content, or for any actions taken in reliance thereon. EXL EVENTS, INC. EXPRESSLY DISCLAIMS ALL WARRANTIES, EXPRESSED OR IMPLIED, AS TO THE ACCURACY OF ANY THE CONTENT PROVIDED, OR AS TO THE FITNESS OF THE INFORMATION FOR ANY PURPOSE. Although ExL makes reasonable efforts to obtain reliable content from third parties, ExL does not guarantee the accuracy of or endorse the views or opinions given by any third party content provider. ExL presentations may point to other Internet sites that may be of interest to you, however ExL does not endorse or take responsibility for the content on such other sites



# ctions/2014 fatient

and Strengthen Relations with ePatients Multiple Stakeholders Showcasing Industry's Best Practices to Connect

# Iop 5 Reasons to Attend

online patient communities

ePatients and the impact on health outcomes and patient Learn about how multiple stakeholders interact with

social media when trying to understand the regulatory landscape of ▶ Examine the challenges that industry and ePatients face

- digital tools to connect with online patient communities pharmaceutical companies use social media platforms and ▶ Through case studies, gain a better understanding of how
- engagements to strengthen stakeholder relationships with ► Explore the use of third party contributors and multichannel generating tailored content applicable in healthcare

▶ Discuss the evolution of the ePatient and it's role in

# SEPTEMBER 15-16, 2014 • WYNDHAM PHILADELPHIA HISTORIC DISTRICT HOTEL

To Register call 866-207-6528 or Visit us at www.exlpharma.com/epatcon





registration@exlpharma.com



866-207-6528

# To Register:



