STRENGTHENING PATIENT ADVOCACY RELATIONS ACROSS THE LIFE SCIENCES

Gathering as an Industry to Explore Patient Advocacy Opportunities through Communication Strategies Used to Initiate Global Patient Group Outreach, Quantifying a Patient Advocacy Program to Prove Value as well as Identifying a Logical Patient Integration Timeline Within Varying Stages of Product Development

PROGRAM OVERVIEW

Advancements in the identification of diseases presents a unique opportunity for pharmaceutical and biotech companies to leverage the integration of direct patient involvement early on within product development through optimization of the patient advocacy relations function. Today, more often than not, patients are increasingly self-educating through the internet, social media outlets and local patient groups. Nevertheless, industry insight and education will prove invaluable and is an integral part of fully understanding a disease as well as treatment options, and as such, patients will look to patient advocacy executives for additional support.

DISTINGUISHED PRESENTERS INCLUDE:

Jamie Ring  
Vice President, Global Patient Advocacy  
GENZYME

Kristen Binaso, RPh, CCP, FASCP  
Associate Director, Patient Advocacy & Professional Relations  
BOEHRINGER INGELHEIM

Melissa Marvel, MPH  
Associate Director Patient Advocacy, Multiple Sclerosis  
GENZYME

Carrie Burke  
Director, Alliance Development  
SHIRE HGT

Mary E. Cobb  
Senior Vice President,  
Membership & Organizational Strategy  
NORD

Wendy Erler  
Associate Director Advocacy Relations  
BIOGEN IDEC

Rumana Haque-Ahmed  
Senior Director Regulatory Affairs  
GENZYME

Kathy Gram  
Director Patient Advocacy  
MILLENNIUM PHARMACEUTICALS

Dr. Sharon Henry  
VP and Head, Global Medical Advocacy  
BRISTOL-MYERS SQUIBB

Joel Beetsch  
Vice President, Patient Advocacy  
CELGENE

Stephanie S. Okey, M.S.  
Head of North America, Genetic Diseases  
GENZYME

Seth D. Ginsberg  
President  
GLOBAL HEALTHY LIVING FOUNDATION

Ken Deutsch  
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Pam Swenk  
Executive Director  
LEUKEMIA & LYMPHOMA SOCIETY (LLS)

Mary Faulkner  
Senior Manager, Grant Management Department  
ABBVIE

Amber Spierer, MPH  
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Associate Director, Patient Advocacy & Investigator Relations  
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SVP, Corporate Communications  
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Janet Hieshetter  
Executive Director  
DYSTONIA MEDICAL RESEARCH FOUNDATION

Tekisha Everette  
Managing Director, Federal Government Affairs  
AMERICAN DIABETES ASSOCIATION

Eileen O’Brien  
Director of Search & Innovation  
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Valerie Carter  
Senior Vice President  
JPA

Rose Gerber  
Director of Communications & Patient Advocacy  
COMMUNITY ONCOLOGY ALLIANCE

Dr. Timothy Miller  
US Medical Director, Genetics  
GENZYME

Katie White  
Communications Manager  
LUNDBECK

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Hyatt Place Chicago River North - Lobby

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CONFERENCE LOCATION:  
Maggiano’s Little Italy - Banquet Facility  
516 N Clark St Chicago IL

HOTEL LOCATION:  
Hyatt Place Chicago - River North  
66 W Illinois St, Chicago, IL

Please refer to back page of agenda for information on Remote Access Passes
1:30  PATIENT AWARENESS CASE STUDY: THE NATIONAL MULTIPLE SCLEROSIS SOCIETY'S EVERYDAY MATTERS CAMPAIGN SUPPORTED BY GENZYMEx, A SANOFI COMPANY

The National MS Society, supported by Genzyme, a Sanofi company, is a nationwide program which featured authentic stories of five people facing everyday challenges that Multiple Sclerosis can bring on the path to one’s best life. Participants leveraged positive psychology to address their personal challenges or opportunities. Participant journeys were shared on a website through video, journals and comprehensive toolkits enabling the MS community to join in. Each participant represented the top-rated topics as voted on by the community including Relationships, Empowerment, Wellness, Family and Work. In this example, Genzyme’s support made it possible for individuals with MS to work together with The National MS Society, a life coach, an Emmy award-winning producer, and a researcher and teacher of positive psychology, to synergistically inform and empower the MS community.

- Working with advocacy groups, patients and external experts to promote patient awareness
- Methods in maximizing patient engagement in their own health
- Identifying the needs of the patient to help discover solutions

Melissa Marvel, MPH, Assoc. Director Patient Advocacy, Multiple Sclerosis
GENZYMEx

2:20  APPROACHES IN MAINTAINING INTEGRAL PATIENT RELATIONSHIPS DURING CLINICAL TRIAL DELAY

Throughout a clinical trial varying delays or program changes may arise at any time, and it is important to have a communication strategy in place in order to keep participants and patient advocacy organizations informed. Industry executives will likely require the involvement and support of advocacy organizations as their development programs advance, and as such, showcasing existing partnerships or having a plan of action in place prior to the time of a trial. Untimely dissemination of information could cause frustration and concern among trial participants, which could in turn cost pharmaceutical companies more time and money through having to start from square one with trial recruitment.

- A case study example on overcoming data failure
- Keeping a positive tone on communication delays or failures
- Exploring the most efficient communication paths

Timothy Saccavino, Senior Vice President, Corporate Communications
ACORDA THERAPEUTICS, INC.

3:10  COFFEE & NETWORKING BREAK

3:40  PATIENT PERSPECTIVE PANEL DISCUSSION: ADDRESSING ADVANTAGES AND CHALLENGES OF INDUSTRY PARTNERSHIPS

The patient voice is one of the most powerful tools influencing drug manufacturers today. Hearing directly from 3-4 varying patient advocate leaders on strategies in which pharmaceutical executives are able to better understand the advocacy landscape will prove to be invaluable. In order to identify and create meaningful partnerships with an ideal patient advocate group, it is essential to understand the objectives and goals of patient advocates. A successful partnership stemming from congruent goals and objectives will prove to be mutually beneficial; wherein by the advocacy group will receive the support and funding needed for treatment and the industry will gain increased exposure in the market.

- Hear 3-4 varying patient viewpoints of a valuable industry partnership
- How the patient perspective differs from the industry perspective
- Enhancing the relationship between industry executives and patients

Tekisha Everette, AMERICAN DIABETES ASSOCIATION
Pam Swenk, LEUKEMIA & LYMPHOMA SOCIETY
Janet Hieshetter, DYSTONIA MEDICAL RESEARCH FOUNDATION
Rose Gerber, COMMUNITY ONCOLOGY ALLIANCE
Mary E. Cobb, NORD

4:30  SHEDDING LIGHT ON PATIENT EDUCATION GRANT PROCESSES WHILE ALSO MAINTAINING TRANSPARENCY

Possessing an advanced knowledge of patient education grant processes, review and compliance standards that strengthen communities and work toward furthering education among the patient population is an integral skill within the advocacy executive role. It is also essential to render methods that will uphold the principle of transparency when it comes to providing grants to medical, scientific, patient and civic organizations through full disclosure and reporting. Many pharmaceutical companies are continuously striving to improve patient education grant processes with the goal of ensuring regulatory compliance, while also providing grants that accelerate the translation between research and into quality patient care.

- Outlining where funding is going
- Opportunities to support educational programs & community programs
- Optimal groups for educational grants & charitable contributions

Mary Faulkner, Senior Manager, Grant Management Department
ABBVIE

5:20  DAY ONE CONFERENCE CONCLUDES
7:30 REGISTRATION & LIGHT BREAKFAST
8:00 CHAIRPERSON OPENING REMARKS
8:10 IMPLICATIONS OF THE PATIENT PROTECTION & AFFORDABLE CARE ACT ON PATIENT ACCESS TO TREATMENT
With the recent implementation of the Patient Protection & Affordable Care Act (ACA) and the more than 32 million Americans that will now have access to care, comes a need for patient advocacy executives to assess and evaluate their role in educating patients on the changes among access to treatments. Understanding the impact of factors such as the substantial growth of Accountable Care Organizations (ACO’s), as well as the emerging differences among insurance coverage that will vary from state to state, is going to become increasingly important within the patient advocacy relations role.
- Investigating uncertainties on the impact of the ACA on patient access
- Effects the ACA will have on reimbursement
- Communication tools used to educate patients on changes

Carrie Burke, Director, Alliance Development
SHIRE HGT

9:00 BIOGEN IDEC PATIENT PARTNERSHIP CASE STUDY
Locating sponsorship or partnership opportunities prior to having an approved product on the market is a strategy that many biotech companies are employing in order to establish a stronger presence within patient communities. BioGen Idec Hemophilia has joined together with the hemophilia community to provide financial support and scientific leadership for the recent My Life, Our Future initiative which is moving worldwide as a push for progress in hemophilia genotyping. This effort is working to offer genotyping at little or no cost while also establishing advancements in treatments for the 18,000 people affected by this severe medical condition. This case study will provide industry executives with methods to use in locating fitting patient groups as well outline the advocates roles and responsibilities in maintaining the partnership.
- Lessons learned: Creating successful & compliant early phase partnerships
- Benefits of partnering with community initiatives through providing funding support & scientific leadership

Wendy Erler, Associate Director Advocacy Relations
BIOGEN IDEC

9:50 COFFEE & NETWORKING BREAK
10:20 IMPLICATIONS OF THE STAR REPORT FOR PHARMA & BIOTECH INDUSTRIES: SUCCESSFULLY TARGETING ADVOCACY RELATIONS
Working with advocacy organizations is an effective way for pharmaceutical and biotech companies to help advance their goals and initiatives, and meet patients’ needs. Advocacy groups are actively partnering with industry in a variety of ways to support their missions and maximize impact. The question is, which activities are most impactful and which companies are getting advocacy “right”? Come hear more about the STAR (Successfully Targeting Advocacy Relations) report, syndicated market research benchmarking advocacy groups perspectives on their relationship with industry.
- Understand where advocacy group needs are being met along with what gaps exist to help companies like you build & enhance your engagement
- Industry & advocacy executive representatives discuss challenges faced in these relationships and ways they have adapted their approach
- How companies can become more patient-centric to meet mutually beneficial goals with advocates

Amber Spierer, MPH, Vice President
MARK KRUEGER & ASSOCIATES, INC.

11:10 CASE STUDY: SUSTAINING A ROBUST ON BOARDING CRITERION FOR SELECTING PATIENT GROUPS
With a plethora of established patient groups for any given disease, it is important for patient advocacy executives to establish and uphold a certain standard when deciding which organizations to work with. Implementing a needs-based assessment when surveying prospective advocate groups will assist in alleviating questions of compatibility as well as reputation; in turn saving the time and effort of both industry executives and patients. Hearing numerous case study examples from a pharmaceutical company that has an established internal patient advocacy function and has built several patient group partnerships will prove extremely beneficial to life science organizations looking to take their partnership on boarding process to the next level.
- Guidance on classifying prospective patient groups
- Recognizing and ruling out incompatible organizations
- Upholding principles throughout selection processes

Kristen Binaso, Associate Director, Patient Advocacy & Professional Relations
BOEHRINGER INGLEHEIM

12:00 LUNCHEON FOR ALL ATTENDEES, SPEAKERS & SPONSORS
1:30 SHEDDING LIGHT ON PERMISSIBLE COMMUNICATION STRATEGIES USED WITH INTERNATIONAL PATIENT ADVOCATES
As patient advocacy continues to play an increasingly integral role across the life science industry within the United States, an opportunity arises in which to explore the use of working with international patient groups in order to maximize advocacy efforts on a global scale. The accepted rules and regulations of communicating directly with patient advocates in other countries are extremely stringent and pharmaceutical companies are seeking further clarification within this area, as each country varies greatly. Patient advocates and professionals must identify best practices prior to the time of global outreach to ensure a compliant and progressive global program.
- Getting started on a global outreach program
- Identification of worldwide patient groups
- Case study insight on effective international patient advocacy efforts

Dr. Sharon Henry, Vice President and Head, Global Medical Advocacy
BRISTOL-MYERS SQUIBB

2:20 UTILIZING SOCIAL MEDIA OUTLETS TO PROVIDE GENUINE CONTENT TO PATIENT GROUPS & DRIVE BUSINESS RESULTS
It is no secret that today’s patient population is increasingly using online resources as a means to self educate as well as locate support groups and advocate leaders within a specific disease. With an emerging trend of the ePatient, more and more pharmaceutical companies have begun to test the waters by incorporating social media into industry patient outreach efforts. Implementing social media in order to create an open forum dialogue for patients will not only enable the target audience to feel more educated and involved in their disease, it will also provide patient advocacy professionals with a means to measure the effectiveness of such campaigns.
- Terms of use: Reviewing a timeline of overcoming regulatory challenges
- Outlining adaptable goals of social media efforts
- Crisis management: Overcoming communications within social media

Katie White, Communications Manager
LUNDBECK

3:10 COFFEE & NETWORKING BREAK
3:30 CASE STUDY: INITIATING GRASSROOTS COMMUNICATION STRATEGIES TO IMPROVE PATIENT ADHERENCE
Patient advocacy groups provide an excellent channel for industry advocates to easily approach patients in better understanding diseases as well as providing enlightenment on strategies to proactively reach overall health goals through proper treatment adherence. Global Healthy Living Foundation president Seth Ginsberg has successfully worked with rheumatoid arthritis patients by building an advocacy landscape to help patients understand that movement towards health improvement cannot be obtained unless medication regimens are upheld throughout recovery. This case study will provide forward thinking strategies of building patient outreach in order to increase adherence and enable patients to take ownership of their health.
- Grasping patient journey of rheumatoid arthritis
- Influence of patient advocates on adherence
- Exploration of grassroots as well as social media approaches

Seth D. Ginsberg, President
GLOBAL HEALTHY LIVING FOUNDATION

4:20 CASE STUDY: ESTABLISHING MEANINGFUL RELATIONSHIPS WITH CAREGIVERS TO AID IN THE MAXIMIZATION OF PATIENT SUPPORT
While the top priority of patient advocacy professionals is to educate and support the patient, it is also critical to account for the significance of the caregiver’s role and direct involvement within the patient’s well being. In times when the patient may be indisposed or unreachable, the caregiver will likely serve as the intermediary and will play a vital role in lines of communication as well as provide added support with patient adherence. As such, it is becoming increasingly important to hear from one pharmaceutical organization who has established communication strategies and best practices when creating relationships with caregivers through their Caring for the Caregiver program that is currently in use among 45 varying patient cases.
- Assisting caregivers in understanding policy & access changes
- Approaches to ensuring caregiver support

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MILLENIUM PHARMACEUTICALS

5:10 CLOSING REMARKS & CONFERENCE CONCLUDES
2ND ANNUAL STRENGTHENING PATIENT ADVOCACY RELATIONS ACROSS LIFE SCIENCES
CHICAGO, IL | JULY 30-31, 2013

WHO SHOULD ATTEND:
Executives that will find this program of greatest relevance are those currently working within the patient advocacy relations departments of pharmaceutical and biotech corporations. Job titles of those executives that will find this program to be most applicable to their job functions include VPs, Directors and managers of:

- Patient Advocacy
- Patient Advocacy Relations
- Patient Advocacy and Professional Relations
- Patient Education
- Patient Communications
- Corporate Communications
- Public Policy
- Public Affairs
- Patient Access Programs

SPONSORSHIP OPPORTUNITIES:
At this time, there are many sponsorship and exhibition opportunities available for companies wishing to increase their visibility and participation in the program, ranging from keynote speaking opportunities through to exhibitor and documentation sponsors. Organizations most suitable include VPs, Directors and managers of:

- Case Management Services
- Patient Communications
- Patient Outreach
- Grant Development Support
- Mapping/Global Assessment of Patient Advocacy Groups (PAGs)
- Development of Models for Ongoing Patient Engagement
- Community Events
- Advocacy Partnerships

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PREVIOUS ATTENDEES INCLUDE:
Sen. Mgr., Public Affairs, Global Patient Relations, ABBOTT
Manager, International Public Affairs, ABBOTT
Dir., Consumer Comm. & Outreach, ACORDA THERAPEUTICS
Director of Patient Advocacy Relations, ALLERGAN
Dir. Patient Advocacy & Public Policy, AMICUS THERAPEUTICS
Assc. Director, Investor Relations, AMICUS THERAPEUTICS
Director, R&D Strategic Relations, AMYLIN PHARMACEUTICALS
Advocacy & Medical Education, ARIAD PHARMACEUTICALS
Associate Strategic Relations Director, ASTELLAS PHARMA US
Senior Marketing Mgr., Patient Marketing, AVEO ONCOLOGY
Customer Marketing Director, BAYER HEALTHCARE PHARMA
Senior Manager of Public Affairs, BIOGEN IDEC
Sen. Dir., Govt. Relations & Alliance Development, BIOGEN IDEC
Director of Marketing & Community Relations, BIOGEN IDEC
Manager, Patient Advocacy, BIOMARIN
Assc. Dir. Patient Advocacy & Investigator Relations, BIOMARIN
Director, Corporate & Public Relations, CELGENE
Director, Advocacy, CELGENE
Director, Advocacy Development, DAIICHI SANKYO
Director, Global Advocacy & Professional Relations, ELI LILLY
Dir., Public Policy & Professional Relations, FOREST LABORATORIES
Director, Patient Advocacy, GENOMIC HEALTH
Associate Director, US Patient Advocacy, GENZYME
Director of Global Market Development, GENZYME
Genzyme Case Manager, Care Coordination, GENZYME
Associate Director, Corporate Communications, GENZYME
Senior Manager, Public Affairs, GILEAD SCIENCES CORP
Director of Advocacy & Alliance Development, GSK
State Advocacy & Alliance Development, GSK
Senior Director Scientific Advocacy, JANNSEN
Epilepsy Marketing, LUNDBECK
Manager Advocacy & Patient Support, LUNDBECK
President & CEO, LUPUS FOUNDATION OF AMERICA
Advocacy Manager, MEDIMMUNE
Vice President, MEN’S HEALTH NETWORK
Manager, Patient Advocacy & Philanthropy, MILLENNIUM
Associate Director Patient Advocacy, MILLENNIUM
Patient Education & Advocacy Manager, MYRIAD GENETICS
Patient Advocacy Lead, NOVARTIS VACCINES & DIAGNOSTICS
Assoc. Dir., Patient Relationship Marketing, NOVO NORDISK
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Patient Affairs Liaison, PFIZER
Director, Patient & Professional Advocacy, PTC THERAPEUTICS
Chief Executive Officer, RITZ COMMUNICATIONS
Director Partners in Patient Health, SANOFI
Assc. Dir., Scientific Patient Communications, SHIRE HGT
Vice President of ADHD Patient Advocacy, SHIRE
Manager of Patient & Customer Excellence, SHIRE
Director of Patient Advocacy, SHIRE
Director of US Marketing, SHIRE REGENERATIVE MEDICINE
Community Liaison, SHIRE REGENERATIVE MEDICINE
Senior Marketing Communications Manager, SHIRE
Senior Manager, Government & External Relations, SHIRE
Sen. Dir. Corporate Comm., SUNOVION PHARMACEUTICALS
Associate Director, Head of US Medical Advocacy, TEVA
Dir., Patient Advocacy & Corporate Social Responsibility, VERTEX
Global Director of Public Relations & Advocacy, VIROPHARMA
Exec. Dir., Govt. Affairs & Patient Advocacy, ZIOPHARM ONCOLOGY

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