STRENGTHENING PATIENT ADVOCACY RELATIONS
ACROSS THE LIFE SCIENCE INDUSTRY

Bringing Light to Patient Advocacy within the Industry through Identifying Innovative Communication Channels to Increase Patient Awareness, Gaining Internal Support In Order to Develop and Manage a Successful Patient Advocacy Program and Effectively Bringing End-User Insight to the Internal Team to Maximize Patient Centricity

PROGRAM OVERVIEW:

Across the industry, the focus on patient advocacy has intensified as the end-user continues to self-educate and demand more consideration and accountability from pharmaceutical and device companies. The role of the patient advocacy executive is becoming increasingly important as they work to further relationships with patient advocacy groups, as well as non-profit organizations to ensure a strong and positive presence within patient communities while maintaining company objectives.

Central to this program will be a vast knowledge share surrounding the changing role of patient advocacy relations across the industry, innovative tools being used to optimize patient education as well as methods used to gain internal support in order to develop and manage successful patient advocacy programs. There will also be opportunities to share best practices on making the transition from sponsorship to partnership when working with patient groups and hearing directly from a patient’s perspective on how industry executives can better understand the advocacy landscape.

This two-day executive level program will provide participants with extensive networking as well as in-depth learning through interactive sessions, panels and case studies, complemented by multiple networking opportunities with industry peers, speakers and service providers. Attendees will have the opportunity to learn strategies for overcoming key challenges involved in the patient advocacy relations role across the life science industry while capitalizing on important opportunities. Through fostering a sense of collaboration, this unique conference program will inspire innovation and help bring clarity to pharmaceutical, biotech and medical device patient advocacy relations professionals that wish to maximize their impact on the industry as well as within the patient community.

MEDIA PARTNERS:

DISTINGUISHED PRESENTERS INCLUDE:

Jamie M. Ring
Senior Director, Patient Advocacy
GENZYME

Kathy Gram
Associate Director Patient Advocacy
MILLENNIUM PHARMACEUTICALS

Geraldine Carroll
Director, Patient Advocacy Relations
ALLERGAN

Sara Chenault
Director, Patient Advocacy
GENOMIC HEALTH

MaryEllen Baker
Advocacy Development Manager
MEDIMMUNE

Cindy North
Customer Marketing Director
BAYER HEALTHCARE

Amy Neach
Case Manager, Care Coordination
GENZYME

Sylvia Wallace
Case Manager, Care Coordination
GENZYME

Lori Gorski
Director of Communications
GENZYME

Jess Rabourn
Founder and Co-Director
PARTNERSHIP FOR COMPASSIONATE USE THERAPIES (PCUT)

Jayne Gershkowitz
Senior Director, Patient Advocacy & Public Policy
AMICUS THERAPEUTICS

Diane M. Goetz
Director, Patient and Professional Advocacy
PTC THERAPEUTICS

Kristina Broadbelt
Global Dir. of Public Relations & Advocacy
VIROPHARMA

Amy West
Associate Director, Patient Relationship Marketing
NOVO NORDISK

Kip Cross
Manager Patient Advocacy & Philanthropy
MILLENNIUM PHARMACEUTICALS

Scott T. Williams, MPA
Vice President
MEN’S HEALTH NETWORK

Sara Pellegrino
Associate Director, Investor Relations
AMICUS THERAPEUTICS

Judi Rising
Founder
PATS FUND & AUTOIMMUNE ADVOCACY ALLIANCE

Penelope C. Fletcher
President and CEO
LUPUS FOUNDATION OF AMERICA, DC/MD/VA
DAY ONE / MONDAY, JULY 30 / STRENGTHENING PATIENT ADVOCACY RELATIONS ACROSS LIFE SCIENCES

7:30 REGISTRATION & CONTINENTAL BREAKFAST
8:20 CONFERENCE WELCOME & CHAIRPERSON OPENING REMARKS
8:30 KEYNOTE PANEL DISCUSSION: SUCCESSFULLY DEVELOPING THE EMERGING ROLE OF PATIENT ADVOCACY RELATIONS ACROSS THE LIFE SCIENCES

In recent years, the role of the patient advocacy relations executive across the life sciences has emerged from a responsibility of marketing or corporate communications departments to a function all of its own. Depending on the size of the company, the role may be thoroughly established and have an entire department in place, or a recently created function that is still in the stages of fully developing responsibilities, objectives and goals. A case study examination of a company that has built a patient advocacy relations department from the ground-up will prove to be extremely beneficial to companies that are looking to enhance this role.

• A definition of the current role of patient advocacy relations
• Exploring the benefits of the increased presence of this role
• What the future holds for patient advocacy relations

MODERATOR:
Jamie M. Ring, Senior Director, Patient Advocacy
GENZYME

PANELISTS:
Geraldine Carroll, Director, Patient Advocacy Relations
ALLERGAN
MaryEllen Baker, Advocacy Development Manager
MEDIMMUNE

9:20 GAINING INTERNAL SUPPORT IN ORDER TO DEVELOP AND MANAGE A SUCCESSFUL PATIENT ADVOCACY PROGRAM

One of the most important aspects of a successful patient advocacy relations program is to have continued support and buy-in from internal employees. Identifying effective methods to utilize in order to gain endorsement from the executive team as well as the ability to advise development, commercial and other internal partners on optimal approaches for advocate interactions is critical in the role of patient advocacy relations executives across the life science industry. Coordinating with marketing and corporate communications teams to ensure that their goals are in line with the goals of the patient advocates will ultimately lead to the success of the company as a whole.

• Tactics in securing corporate buy-in
• Methods used to gain internal executive support
• Managing program to optimize advocacy relations

Kathy Gram, Associate Director Patient Advocacy
MILLENIUM PHARMACEUTICALS

10:10 COFFEE & NETWORKING BREAK

10:30 AN INSIDE LOOK INTO PATIENT ADVOCACY THROUGH CASE MANAGEMENT

• Working with patients and healthcare providers to support access to optimal care
• Establishing relationships to increase patient education and coordinate access to treatment
• Dedicated to helping patients and their families connect with all resources available to them
• Maintain patients’ treatment by addressing on-going needs

Amy Neach, Case Manager, Care Coordination
GENZYME
Sylvia Wallace, Case Manager, Care Coordination
GENZYME

11:20 CORPORATE PHILANTHROPY: INCREASING PARTICIPATION OF INTERNAL EMPLOYEES IN COMMUNITY OUTREACH

The community relations involvement efforts of internal employees are central to maximizing relations among patient advocate leaders. Whether it is fundraising for charity or working with local schools to increase math and science knowledge, increasing the presence of pharmaceutical, biotech and device companies within the community will surely assist in gaining the awareness and trust of the end-user. Encouraging employees to work with organizations on a local level will enable life science companies to better understand and support concerns and issues among patient communities.

• Initiatives used to increase employee participation
• Examining the ROI of community involvement
• Aligning company goals with non-profit organizations

Kip Cross, Manager, Patient Advocacy & Philanthropy
MILLENIUM PHARMACEUTICALS

12:10 LUNCHEON FOR ALL ATTENDEES, SPEAKERS, AND SPONSORS

1:30 A PATIENT PERSPECTIVE ON BUILDING EFFECTIVE RELATIONSHIPS WITH ADVOCATE GROUPS

In order for pharmaceutical and medical device companies to identify and create partnerships with an ideal patient advocacy group, it is essential to understand the objectives and goals of patient advocate leaders directly from their perspective. This relationship will prove to be beneficial to both groups wherein by the advocacy groups will receive the support and knowledge needed for products and services and the industry will gain increased exposure in the market. Hearing directly from a patient advocate’s viewpoint on how PAR executives can better understand the advocacy landscape through a direct collaboration with advocate groups, especially for those companies that are bringing new therapies to market, will prove to be invaluable.

• Hearing what a patient sees as a valuable partnership with industry
• How the patient perspective differs from the PAR perspective
• Enhancing the relationship between PAR executives and patients

Penelope C. Fletcher, President and CEO
LUPUS FOUNDATION OF AMERICA, DC/MD/VA
Judi Rising, Founder
PATS FUND & AUTOIMMUNE ADVOCACY ALLIANCE (A3)

2:20 BEST PRACTICES IN BRINGING EXTERNAL INSIGHT TO THE INTERNAL TEAM TO ENHANCE PATIENT CENTRICITY

Patients are at the core of today and tomorrow’s healthcare system. Working with marketing and corporate communications departments within the organization to meet the needs of an increasingly proactive patient population is becoming a key responsibility for patient advocacy professionals. Knowing how to effectively transfer patient information that is acquired from advocacy groups back within a pharmaceutical or medical device company to address the unmet needs of the patients will ultimately improve market share, sales, and end-user loyalty for what a patient sees as a valuable partnership with industry. It is essential to develop standards that will uphold and improve the patient centricity within an organization by overcoming resistance or lack of support from internal decision-makers and power brokers.

• Strategies in implementing and maintaining a patient centric mindset
• Successfully implementing insight from the end-user
• A presentation of BioNJ PA survey results

Jaye Gershkowitz, Senior Director, Patient Advocacy & Public Policy
AMICUS THERAPEUTICS
Sara Pellegrino, Associate Director, Investor Relations
AMICUS THERAPEUTICS

3:10 COFFEE & NETWORKING BREAK

3:30 IMPLEMENTING A PLATFORM TO EMPOWER THE PATIENT THROUGH COMMUNICATION OF PRODUCT SOLUTIONS

Many companies across the life science industry are either currently implementing or looking to develop programs to provide an optimized patient experience based on individual needs, preferences. Educating patients on prevention strategies, assistance in finding support communities in the fight against their disease and applying for and securing financial assistance will create a support system which will optimize treatment and management of their chronic disease. Exploring and internally implementing new and innovative ways to educate today’s proactive patient population is an essential part of maintaining patient centricity across the life science industry.

• Case study on the Cornerstones4Care platform
• Empowering patients based on individual needs and disease state
• Creating dialogue to establish meaningful relationships with patients

Amy West, Associate Director, Diabetes Patient Relationship Marketing
NOVO NORDISK

4:20 INNOVATIVE APPROACHES AND COMMUNICATION CHANNELS UTILIZED TO INCREASE PATIENT AWARENESS AND ENGAGEMENT

Patient advocacy executives within the life science industry serve as the internal resource for innovative thinking as it relates to new patient and consumer trends, thus it is critical to remain cognizant of innovative communication channels to utilize in order to maximize presence within the patient community. Whether it is expanding the use of social media, conducting WebEx’s and teleconferences or presenting at advocate organization conferences, investigating the latest developments in communication will increase health and product awareness among the end-user.

• Using social media & online communities in a highly regulated environment
• Analysis of frequent communication tools used by patient advocates
• Creative projects utilized in partnering with advocates

Cindy North, Customer Marketing Director
BAyer HEALTHCARE

5:10 DAY ONE CONFERENCE CONCLUDES
DAY TWO / TUESDAY, JULY 31 / STRENGTHENING PATIENT ADVOCACY RELATIONS ACROSS LIFE SCIENCES

8:00 REGISTRATION & CONTINENTAL BREAKFAST

8:25 CHAIRPERSON OPENING REMARKS

8:30 GENZYME CASE STUDY: PATIENT COMMUNICATIONS DURING A CRISIS
- Best Practices and Lessons Learned while Managing through Recent Product Shortages
- Giving patients a voice: Establishing the right relationships and working with advocacy group partners before, during and after a crisis hits
- Demonstrating commitment: Communicating honestly with patients, even when uncertainty remains
- Patients versus Shareholders: Prioritizing audiences and examining how and when patients receive news during legally “material” crisis-related moments

Lessons learned: Feedback on Genzyme’s crisis communications performance from the patient perspective, and how to restore trust

Jamie M. Ring, Senior Director, Patient Advocacy
Genzyme

Lori Gorski, Director of Communications
Genzyme

9:30 ESTABLISHING PARTNERSHIPS WITH PATIENT ADVOCACY ORGANIZATIONS TO MAXIMIZE PATIENT EDUCATION
With an increase in the presence of patient advocacy relations across the life science industry, comes a need to identify and partner with advocacy organizations in order to increase disease and health awareness and provide a community forum for patients to create dialogue amongst themselves in living with, overcoming and/or preventing chronic disease. Educating patients through collaboration with organizations that have an existing rapport with patient communities will prove to be extremely beneficial to pharmaceutical and medical device companies. Establishing these partnerships is becoming an increasing responsibly of the patient advocacy relations role and when properly implemented will prove to be very beneficial.

- Tactics utilized in maximizing patient education
- Providing patients with a wide range of resources
- Best practices to measure the success of a patient outreach program

Sara Chenault, Director, Patient Advocacy
Genomic Health

10:20 COFFEE & NETWORKING BREAK

10:40 SUCCESSFULLY MAKING THE TRANSITION FROM SPONSORSHIP TO PARTNERSHIP WHEN WORKING WITH PATIENT GROUPS
Gone are the days when pharmaceutical and device companies can contribute sizeable sums of money to sponsor patient advocate group events. With this change comes an increasing trend across the industry where companies have been moving from a sponsorship to a partnership role when working with these groups. Ensuring that the goals and objectives of the advocate organization are in line with those of the pharmaceutical or medical device company is an essential aspect of creating a strong partnership that will prove to be mutually beneficial for both parties. When aligning the objectives of both groups, challenges do arise, therefore hearing from companies that have successfully created partnerships will prove to be valuable to patient advocacy relations executives across the industry.

- Methods in maintaining working partnerships with patient advocate groups
- Identifying an advocacy organization with parallel objectives
- How to overcome challenges faced when creating new partnerships

Scott T. Williams, MPA, Vice President
Men’s Health Network

11:30 INCREASING AWARENESS AND ACCESS TO SPECIALTY DRUGS THROUGH EFFECTIVE PATIENT ADVOCACY RELATIONS
With an increase of the recognition and diagnosis of rare diseases comes an increased need for specialty drugs across the life science industry. A recent survey showed that 13% to 17% of employers have added a specialty category to their drug benefits, and more are likely to adopt them, given that more than 600 specialty drugs are currently in development. It is essential for patient advocacy relations executives within pharmaceutical and medical device companies to work together with patient advocate groups focused on rare diseases, in order to keep them informed on the proper use of the drugs. It is also important to serve as the liaison between the patients and the PAP through collaboration with organizations that have an existing rapport with patient communities will prove to be extremely beneficial to pharmaceutical and medical device companies. Establishing these partnerships is becoming an increasing responsibly of the patient advocacy relations role and when properly implemented will prove to be very beneficial.

- Case study on a PAP for specialty drugs
- Identifying specialty drug patient advocate groups
- Sustainability of treatments for rare diseases

Kristina Broadbelt, Global Director of Public Relations & Advocacy
Viropharma

12:20 LUNCHEON FOR ALL ATTENDEES, SPEAKERS AND SPONSORS

1:30 VENTURE PHILANTHROPY: FUNDING THE DEVELOPMENT OF RARE DISEASE TREATMENTS
With an increased recognition of rare diseases affecting hundreds of thousands of patients worldwide and a lack of treatment options available, a call to action for treatment options was needed. A number of rare disease foundations have decided to invest in various life science companies through a partnership known as venture philanthropy, through which foundations support early-stage product development for pharmaceutical and biotech companies. By creating a network of doctors and organizations to assist in the execution of clinical trials and raising capital to invest in the development of treatment, this endeavor will benefit the drug development company, the investing foundation and most important, the patient.

- A real-time case study on venture philanthropy
- A discussion of potential risks of this concept
- Exploring this endeavor for your company

Diwta M. Goetz, Director, Patient and Professional Advocacy
PTC Therapeutics

2:20 ETHICAL AND ECONOMIC TRADE OFFS OF COMPASSIONATE USE; MAKING EXPANDED ACCESS PROGRAMS VAILABLE
Patients with advanced life-threatening disease who have no options for approved treatment or clinical trial participation may try to gain access to unapproved drugs through compassionate use authorization. Each pharmaceutical and medical device company has its own individual policy regarding expanded access, and in each case the FDA reviewer must agree to the right of use for the particular patient or patient group. It is essential to fully evaluate the hazards and opportunities of these programs, and companies must understand the considerations from commercial, regulatory, and medical perspectives. In an age of near-instant availability of information, rationally minded patients and clinicians will have high expectations for intelligent, ethical compassionate use policies.

- Real and perceived impacts on clinical development
- Balancing medical risk/benefit for different classes of disease
- Emerging models for cost partnership and risk management

Jess Rabourn, Founder and Co-Director
Partnership for Compassionate Use Therapies (PCUT)

3:10 PARTNERSHIP FOR COMPASSIONATE USE THERAPIES (PCUT)

3:10 CLOSING REMARKS & CONFERENCE CONCLUDES

ABOUT THE ORGANIZERS:
Q1 Productions designs and develops webinars, training courses, conference programs and forums aimed at specifically targeted audiences in order to provide strategic and timely information. Through a rigid production process focused on end-user research and design, our team is able to understand the immediate business concerns of today’s leading executives. Whether focusing on new or pending legislative issues, enhanced business processes or technologies that will drive efficiency and customer service, our programs provide solutions to the urgent needs of our attendees.
FEATURED CONFERENCE SPEAKERS:

Jamie M. Ring
Senior Director, Patient Advocacy
GENZYME

Jamie M. Ring is the Senior Director of Patient Advocacy for Rare Diseases at Genzyme Corporation, a Sanofi company. Jamie is responsible for the global management of advocacy activities, supported by a team of 6 individuals located in the US and Europe. Jamie has been with Genzyme for over 6 years. Prior to coming to Genzyme, Jamie worked at Biogen Idec supporting patient programs for both the Multiple Sclerosis and Non-Hodgkin’s Lymphoma disease communities. Additionally, Jamie worked at the ALS Therapy Development Institute as the Associate Director of Programs, responsible for ALS disease awareness initiatives and fundraising campaigns. Jamie holds a B.A. in Sociology from Union College, Schenectady, NY and a Master’s in Public Health from Boston University.

Jayne C. Gershkowitz
Senior Director, Patient Advocacy and Public Policy
AMICUS THERAPEUTICS

Jayne Gershkowitz, active in the rare disease community for almost 14 years, is now bringing her patient advocacy perspective to the broader biotech arena. She is a member of the Steering Committee of the Healthcare Institute of New Jersey, the Government Relations Committee of BIO, recently co-founded the Patient Advocacy Committee of BioNJ which she co-chairs, and is a member of the Program Committee for the 2nd Annual US Conference on Rare Diseases and Orphan Products co-sponsored by NORD and DIA. She serves as Vice President of Education of the Board of Directors of National Tay-Sachs & Allied Diseases Association, and is a former vice chair of NORD-National Organization for Rare Disorders.

SPONSORSHIP OPPORTUNITIES:

At this time, there are opportunities available for companies wishing to increase their visibility and participation in the program. Leading solution providers will be represented by their executive team and will join the delegation in high level meetings and closed discussions. Organizations most suitable for this type of exposure provide services and solutions including but are not limited to:

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

WHO SHOULD ATTEND:

Executives that will find this program of greatest relevance are those currently working within the patient advocacy relations departments of pharmaceutical, biotech, medical device and diagnostic 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 Relations
- Patient & Professional Advocacy
- Patient Relationship Marketing
- Advocacy Development

PREVIOUS PARTICIPANTS IN Q1 CONFERENCES INCLUDE:

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