"Together we have the unique opportunity to improve the lives of patients around the globe."



) World Patients Alliance

WPA Fundraising Webinar

Welcome and Introduction



Andrew Spiegel, Esq. Executive

WPA Board Chair

Andrew Spiegel is the Chair of World Patients Alliance. He has nearly two decades of experience in the patient advocacy arena. Spiegel co-founded the Colorectal Cancer Alliance, now the leading US based national patient advocacy organization dedicated to colon cancer. Spiegel is also the co-founder and executive director of the GCCA, an international patient advocacy organization of nearly 50 colon cancer patient advocacy organizations and stakeholders dedicated to end the worldwide suffering of the 3rd leading cause of cancer deaths.



Who We Are

The World Patients Alliance (WPA) is a nonprofit umbrella organization of patients, patient organizations and stakeholders from around the globe. The WPA provides the platform to empower and raise the patients' voice for the provision of and access to safe, quality and affordable healthcare.

WPA works to ensure patients have an active role to play in all the stages of healthcare that including planning, provision, monitoring, research and evaluation of health services.

There are no fees for Patient Advocacy Organizations to become members, and our programs and initiatives are at no-cost to our Patient Advocacy Organization members.

Established: 2019

Official Launch: Sept 2020

Founding Board

- Chair: Andrew Spiegel, Esq. Executive Director, Global Colon Cancer Association
- Secretary: Penney Cowan. Founder & CEO, American Chronic Pain Association
- Treasurer: Jolanta Bilinska Director of Development & Social Communication, City Medical Centre
- Director: Karla Ruiz de Castilla CEO, Esperanta and Latin American Union Against Lung Cancer
- Director: Regina Kamoga Executive Director, Community Health & Information Network
- Executive Director: Hussain Jafri, PhD. Secretary General, Alzheimer's Pakistan



Patient Advocacy Group Members



Representing All Diseases









Agenda

Sr. #	Topic	Speaker		
1.	Welcome and Introduction to the workshop	Andrew Spiegel		
2.	Introduction to Fundraising	Mike Splaine.		
3.	How foundations fund NGOs	Michael S. Marcus		
4.	How best to work with industry?	Patti Jewell		
5.	Can working with industry benefit patients?	Cathy Traz		
6.	Successful fundraising through submitting a funding application	Kenneth Kabagambe		
7	Discussion / Q&A			



Introduction to Fundraising



Michael Splaine.

Owner and Principal in Splaine Consulting

Michael Splaine is Owner and Principal in Splaine Consulting, a small advocacy and government affairs consulting firm based in Washington DC. Immediately prior to starting this company, Mike was Director of State Government Affairs in the Public Policy Division of the US Alzheimer's Association with whom he enjoyed a 23-year career. He is the managing partner of a related company Recruitment Partners LLC focused on improving the pace, quality and diversity of recruitment into dementia clinical trials. Mike is a consultant to the US Alzheimer's Association/CDC Healthy Brain Initiative and recently was the lead on behalf of the Association on its Road Map for Indian Country document and now its related outreach. Mike also serves as a consultant to the International Psychogeriatric Association and the International Indigenous Aging Association.



World Patients Alliance Introduction to Fundraising

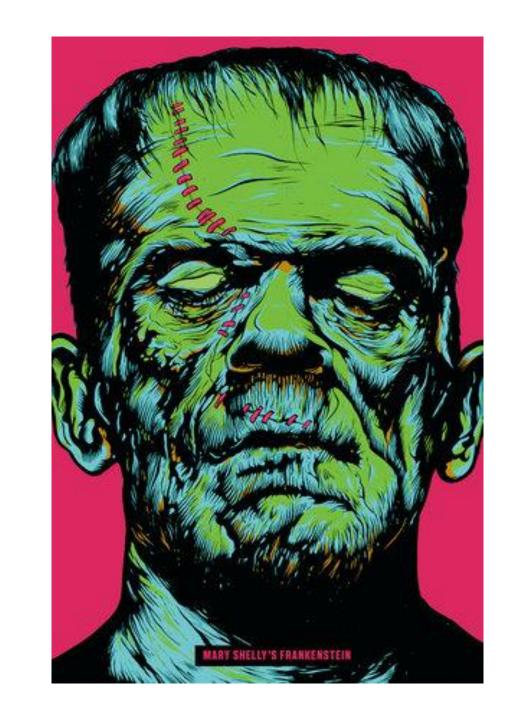
Michael Splaine March 3, 2022

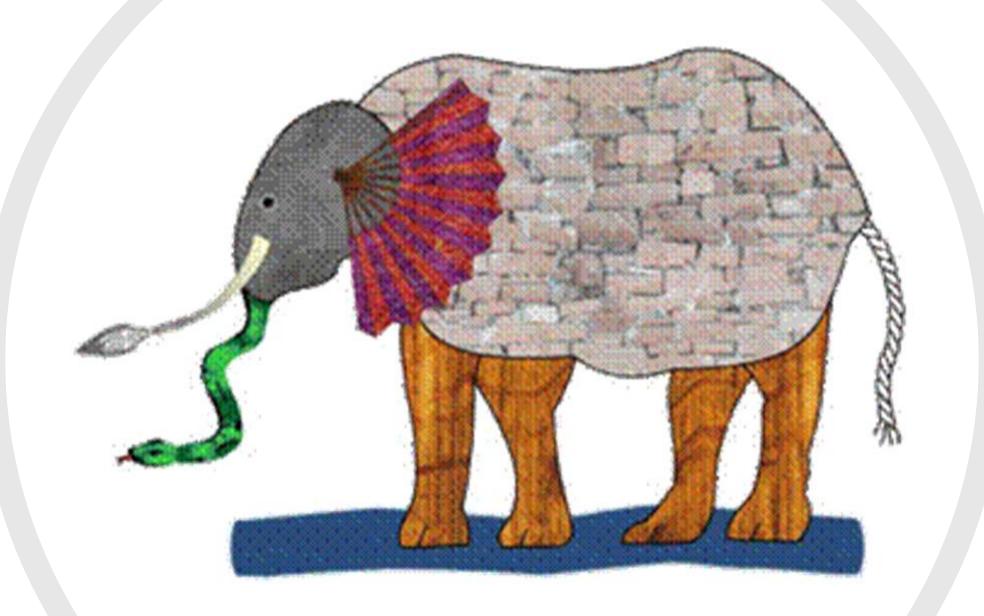


None have directed this talk.

Current Clients

- Nevada Senior Services
- Alzheimer's Disease International
- Alzheimer's Association (National Public Health office)
- International Association for Indigenous Aging (IA²)
- International Psychogeriatric Association
- Neighbor Network Northern Nevada
- NE Indiana Aging Services
- Building Positive Lifestyles/Arc Southern Nevada
- Woolsey Pharmaceuticals
- National Ombudsman Resource Center
- UCSF, UMBC, Emory University, JHMI, UMASS, NWU, MSSM
- Owner: Managing Partner, Recruitment Partners LLC, Owner, Splaine Consulting and Cognitive Solutions LLC





Fundamentals

No Money; No Mission

- Define your unique mission.
- No one loves a problem; name your solution!
- Refine a tag line.



Develop a budget

- Your ideas
- Create a menu of options for funders
- Accountability document
- Fiscal controls



ASK!

- Brainstorm "who cares—or could care"
- •All communities have money.
- Three things at every meeting.
- Teach and brief solicitors.
- Accept useful in kind contributions.
- The magic of a match campaign.

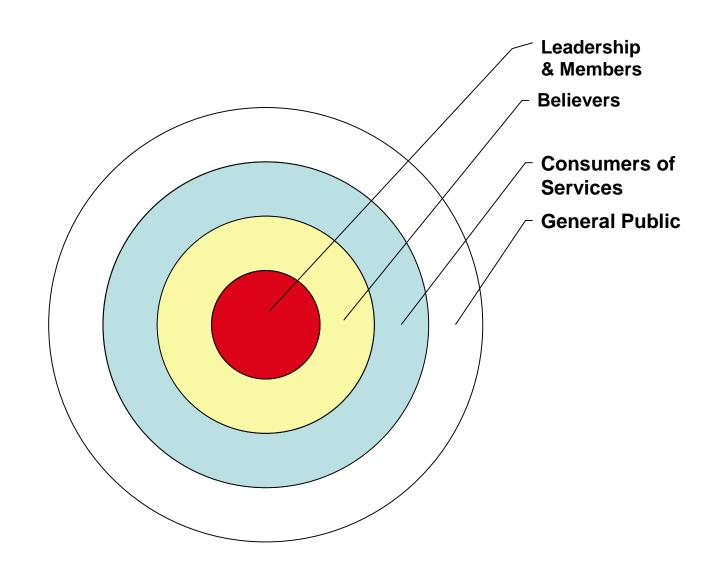


Thank and acknowledge.

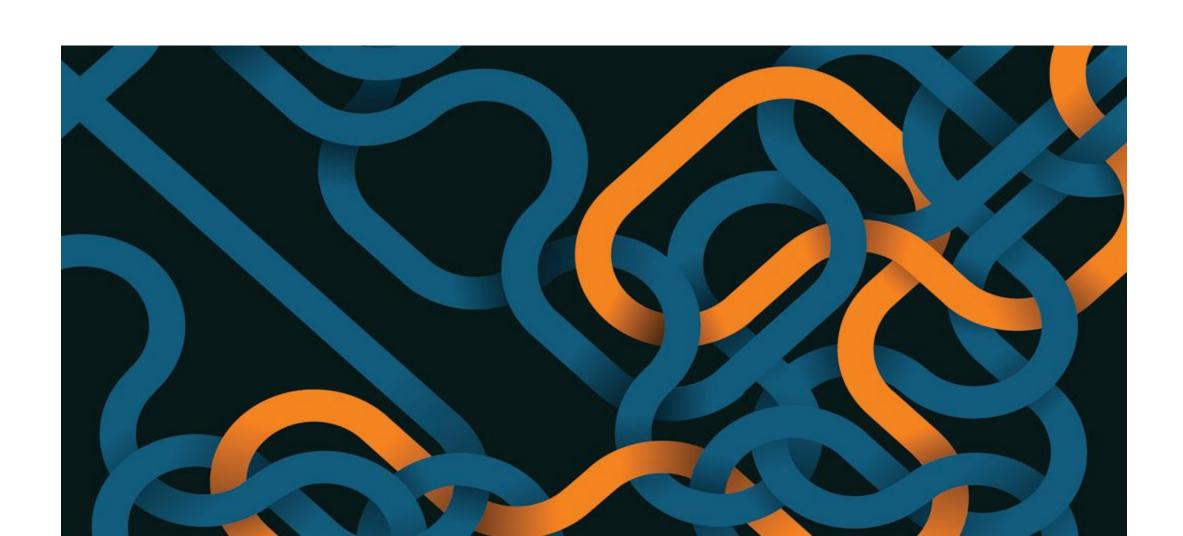
- Folder of letters—promptness.
- Acknowledge without endorsing
- Follow donor wishes.
- Report periodically on progress.



Moving from the Core



Regulation and Accountability



Contact information

- mike@splaineconsulting.com
- 1.443.630.9226
- www.splaineconsulting.com
- Columbia, Maryland USA
- Reference Item <u>The Grassroots Fundraising Book</u> Joan Flanagan Contemporary Books 1992 ISBN 0-8092-5746-7

How Foundations Fund NGOs



Michael S. Marcus

Principal of Consultants for Community Resources

Michael S. Marcus is currently the Principal of Consultants for Community Resources, which provides ABCD consultation to the nonprofit sector, principally those working with older adults and in intergenerational settings. Michael has over 30 years of experience as a grantmaker, manager, organizer, trainer, and facilitator working with organizations, government agencies, universities, and foundations in aging, disability, homelessness, food security, housing, child welfare, and poverty. As a grantmaker, Michael made nearly \$1 Billion in grants to not-for-profit organizations. He has worked as grantmaking from , 1983 to and 1990 with the Villers Foundation, now known as Families USA. Moreover, he has also worked for Chicago Community Trust (CCT) from 1990 to 2004. From 2007 to 2016, Michael led the Harry and Jeanette Weinberg Foundation, which is the largest funder in aging in the United States. Michael has a Doctorate degree and has also taught at leading universities of America.



WPA Fundraising Webinar Foundations 101





Michael Marcus, Principal
Consultants for Community Resources

<u>www.ccr.com</u>
+1 (847) 571-1802



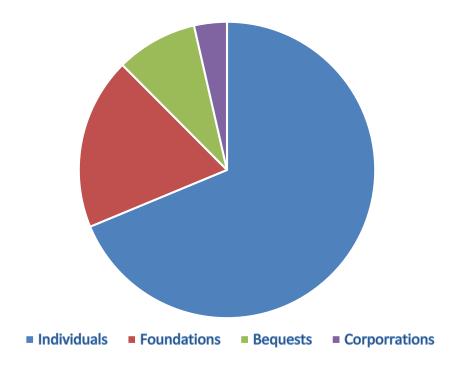
Distinguishing Characteristics of Foundations

FOUNDATION TYPE In the U.S.	SOURCE OF FUNDS	GEOGRAPHIC FOCUS	KINDS OF FUNDS	CHARGE OR PURPOSE	PUBLIC CHARITY
Community: About 3172 Community Foundations in the U.S. (about 760 are active) and roughly 1700 active	Contributions from individuals, families, corporations and other entities	Local community area	 □ Designated, □ Restricted, □ Unrestricted, □ "Hybrid" □ Donor/advisor 	Broad, public benefits, community needs in areas of health, social service, education, arts & humanities, and	Classified as "public charity," favorable tax implications, asset management by community-based trustee banks, public distribution committee
Worldwide Corporate: Approximately 3,000 in the US	Pre-tax Corporate profits	Generally Communities in which corporation does business	N/A	civic affairs Determined by the corporation— scope may be broad or limited	Classified as private, less favorable tax implication, asset management at discretion of corporation, private distribution committee
Independent Family: Approximately Approximately 87,000	Private Assets	Determined by the donors—local, national, or international	N/A	Determined by the donors—scope may be broad or limited	Classified as private, less favorable tax implications, asset management at discretion of the donors, private distribution committee
Conversion: Approximately 200	Sale of not-for profit health providers	Local Community Area	Usually restricted to health	Usually determined by documents of sale	Classified as Public Charity

With thanks to the Chicago Community Trust 2004

Giving USA: Americans Donated an Estimated \$471.44 Billion to Charity in 2020.

- Individuals 69% (\$324.10 Billion)
- Foundations 19% (\$88.55 Billion)
- Bequests 9% (\$41.91 Billion)
- Corporations 4% (\$16.88 Billion)



Funding Priorities & Local Trends in Grantmaking:



How Local Foundations Set Priorities

- Vision/Mission
- Analysis
- Need
- Focus
- Goals/Objectives
- Approach
- Education
- Decision
- Communications Plan





THE GOOD

- Focus
- Impact
- Engaged
- Spirit of collaboration
- Shining stars
- More \$\$\$ more flexibility





THE BAD

- Funders are more savvy!
- Decreased dollars for "start up" funds or new projects?
- Increase in mergers or non-profits not making it
- Reduced contributions to current grantees
- Contributions to fewer organizations









THE UGLY

- Reduction in capital campaign support
- Grantmaking activity suspended
- State and local budget deficits and cuts





What to consider when prioritizing potential funders

- Mission Alignment: How well does your organization fit within the foundation or this particular opportunity's giving criteria?
- **Giving Capacity:** What is the capacity of the foundation and what size grant could they give to your organization?
- Type of funding: Does this funder fund the type of project you are pursuing?
- Relationship: Does anyone in your organization, either staff or a board member, have an existing relationship with someone at the foundation?
- **Timing:** How much time will it take your team to complete the application or next step?

The 10 Commandments of Grantseeking









Soundlites



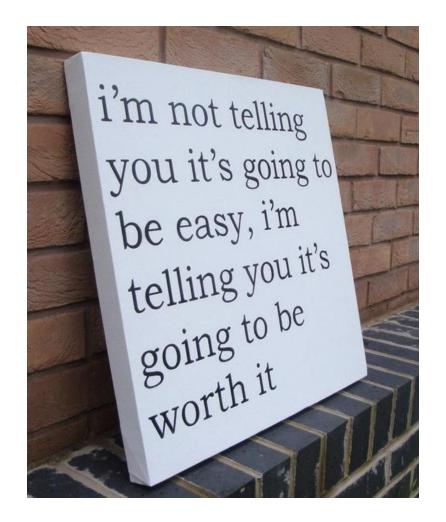
Talk First

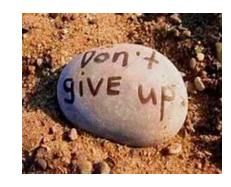


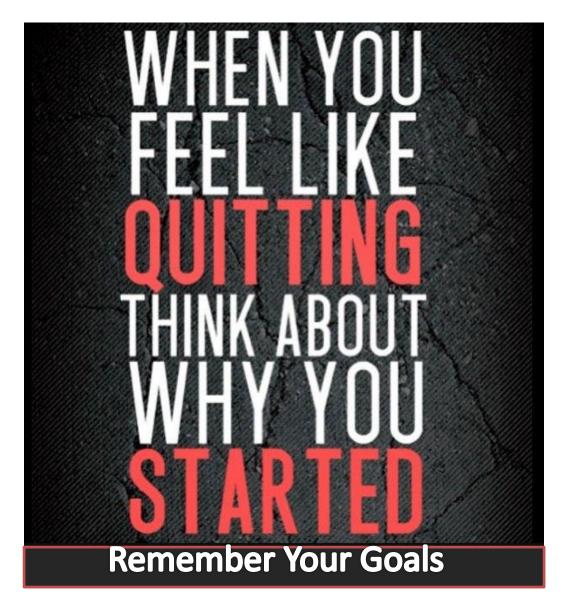




Nurture Relationships







Grantseeker's RESOURCES

The Foundation Center <u>www.fdncenter.org</u>

The Grantsmanship Center <u>www.tgci.com</u>

The Chronicle of Philanthropy http://philanthropy.com

The Council on Foundations <u>www.cof.org</u>

Foundations Online <u>www.foundations.org</u>

Charity Channel http://charitychannel.com

Grants.gov <u>www.grants.gov</u>

Grantseeker's RESOURCES

Philanthropy News Network http://pnnonline.org

Independent Sector <u>www.independentsector.org</u>

Grantmakers In Aging <u>www.giaging.org</u>

Grantmakers In Health <u>www.gih.org</u>

GrantsNet <u>www.grantsnet.org</u>

Community of Science <u>www.cos.com</u>



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How Best to Work with Industry?



Patti Jewell

Senior Director, Patient Advocacy, US Co-Lead,
Pfizer

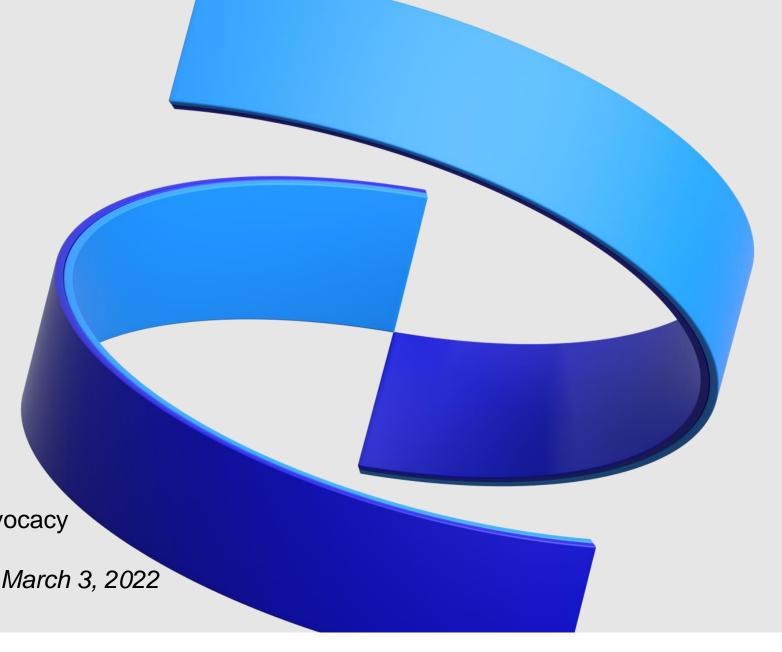
Patti Jewell is Senior Director, Patient Advocacy, US Co-Lead, in Pfizer's Global Health & Social Impact department, focusing on collaborating with patient advocacy organizations across therapeutic areas on public policy and patient centricity initiatives in the US. Prior to this role, Patti led Pfizer's strategic engagements on global and US cancer policy and public affairs matters, focusing on breast cancer related issues as well as a portfolio of pan-tumor topics including health equity and the value of cancer medicines. Patti has also worked in Alliance Development, State Government Relations and Grassroots Advocacy for Pfizer, and was a Legislative Assistant to a United States Senator before joining Pfizer. She received her Masters in Public Administration from New York University and bachelors degree in Political Science from the University of Michigan.



Tips on How Patient Advocacy Groups Can Work with the BioPharmaceutical Industry in Raising Funds to Support their Mission

Patti Jewell, Senior Director, Patient Advocacy

Presentation to World Patients Alliance, March 3, 2022





Ideas for How to Work with Industry

- Patient-focused, oriented around the condition (not on a specific medicine)
- Open and transparent communication discussing areas of mutual interests, goals for the partnership
- Have one person at both the advocacy group and the company as a central point of contact
- Have written agreements in place regarding funding
- Partnerships can be 1:1, multi company or multi stakeholder
- Partnerships/engagements are not always financial may include sharing expertise, participation in in specific work groups, etc...



Common themes across industry, however, differences by company and by country

Commonalities

- Respect for the independence of the patient advocacy organization
- Internal rules govern types of activities to fund
- Budget cycles are usually 12 months
- Require agreements/legal documentation of the funding arrangement

Differences

- Local laws
- Local cultural norms (pharma code, disclosure, cultural acceptability)
- May be differences in how companies define charitable contributions, sponsorships, collaborations, grants, etc...
- May be differences in the types of activities companies support (disease awareness, policy advocacy, research, etc...)



Thank You



Can Working with Industry Benefit Patients?



Cathy Traz

Executive Director & Head of Global Advocacy, Bristol Myers Squibb

Cathy Traz is the Executive Director & Head of Global Advocacy, Bristol Myers Squibb. She has broad advocacy experience gained through leadership roles at Bristol Myers Squibb, Endo Pharmaceuticals, and GlaxoSmithKline. She also gained her expertise in health policy and patient advocacy working for NJ Governor Christine Todd Whitman and The Leukemia & Lymphoma Society respectively. Cathy is the architect of the Advocacy Exchange, a global virtual platform created to unite advocacy organizations, patients, and industry leaders in the exchange of information; PEER, a groundbreaking effort to bring the patient voice into the business - Patient Expert Engagement Resource (PEER); the CEO Roundtable, an ongoing meeting with leaders from patient advocacy groups and corporate to discuss best practices related to access to care and outreach to underserved communities; and also leads Health Equity Advocacy, delivering on commitments announced in 2020, BMS donated funds to 56 nonprofits serving medically underserved populations across the U.S.; as well as many other global initiatives.



ADVOCACY EXCHANGE



















the largest cross-disease, cross cultural, global advocacy Initiative in healthcare

2020-2021

Four Working Groups 1. Racial & Ethnic disparities in Health &

Healthcare

2. Accessibility

3. Patient Voice/ PFMD

Future of Advocacy

39 workstreams co-created by participants including:

- Platform enhancements
- Member resources
- Peer-review of Best **Practices and Pillars**

Media coverage in 13+ outlets, including 8 interviews with TAE spokespeople, reaching 4.6M+ monthly readers

Advocate-defined principles

and best practices driving

change in key TAs:

Solid tumor, Hematology,

Immunology, CV, MS,

Fibrosis, Dermatology,

Mental Health, Rare

Diseases

28 live sessions co-created with advocates: 35+ hours of exclusive, expert video content

328+ advocacy organizations have participated; 50+ have created virtual booths; 5,800+ booth visits

9M+ social media impressions; 25,000+ email opens since inception in 2020

3,825+ people interacted live with 85 advocate, healthcare and BMS thought-leaders

42,362+ people from 148 countries have visited the TAE with 6000+ registrants (28% outside US)

2022

Continued content development and speaker identification that aligns with participant feedback & guidance and supports empowered patients and caregivers

Publication of peer-reviewed & validated white papers & resources including:

- 1. Arc of Advocacy
- 2. The Future of Advocacy: Pillars
- Fixing Disparities: Principles
- Best Practices: Racial & Ethnic Disparities; Access to Care; Patient Voice

Initiative enhancements including

- Expansion into additional TAs and regions by customizing content (Latam, Asia)
- Dedicated social media channels
- Improved user interface on website (ie key word heatmaps and cataloguing of content based on key topics across TAs)



Strategic Ambition for the Advocacy Exchange

ADVOCACY EXCHANGE

Continue the ongoing evolution toward a broader Advocacy Exchange to unite advocacy organizations, patients and industry leaders. Maintain an 'always on' mentality to foster meaningful growth and partnership across disease areas to improve outcomes for patients.

Success will be defined through:

- Increased awareness of and registration for Advocacy Exchange live sessions, expanding participation across disease areas and geographies
- Improved engagement through an enhanced digital platform and dedicated messaging channels



Listening to the Patient - Every Step of the Way

Engaging with advocacy stakeholders helps us uncover insights that inform and inspire our work.

By continuing to infuse the patient advocate voice and perspectives in the discovery, development and delivery of innovative medicines, we're able to affect change and make a difference in patients' lives.



The Patient Expert Engagement Resource (PEER) is an enterprise-wide approach designed to implement expert patient advocate engagement throughout BMS's product development and commercialization continuum

2022 Objectives

Ex-US Expansion

The PEER program will be expanding outside of the US and pilots will be executed in 3-4 countries in 1H of 2022

PEER Digital Solution

a digital solution to foster growth and sustainability and continue to give BMS a competitive advantage (2Q kickoff)

PEER Metrics Dashboard

The dashboard will continue to provide near real-time data and will be incorporated into the PEER digital solution

PEER on BMS.com

A dedicated area on BMS.com for the PEER program to engage and enroll advocacy organizations (legal approval pending; anticipated go live 2Q/3Q)

Turn Learnings into Metrics

Use the feedback obtained from engagements to have a better understanding of what actions were implemented on the insights received from Patient Advocacy organizations and share broadly within BMS (ongoing)

Thank You!

Successful Fundraising through Submitting a Funding Application



Kenneth Kabagambe

Founding Executive Director of the National Organization for People Living with Hepatitis B (NOPLHB)

Kenneth Kabagambe is the Founding Executive Director of the National Organization for People Living with Hepatitis B (NOPLHB), the only patient driven NGO for the rights of Hepatitis B patients in Uganda. He is also a member of the Hepatitis Technical Working Committee of the Ministry of Health, Uganda. Kenneth is also the Past Executive Board Member for the African Region at the World Hepatitis Alliance. He is the brain behind the African Hepatitis Summit 2019 held in Kampala that brought over 600 regional and global leaders working on viral hepatitis for a high-level meeting that led to the Egyptian support towards the treatment of hepatitis C patients in Africa. He is also a Patient Advisory Council Member of Hepatitis Foundation International U.S.A. Kenneth has extensive patient experience in the field of Viral Hepatitis as he has spent most of his life working on advocating for patients' rights in accessing quality diagnosis, care and treatment.



Discussion Q&A

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www.twitter.com/WorldPatients



www.linkedin.com/company/world-patients-alliance/

For more information, visit <u>www.worldpatientsalliance.org</u>
Or email <u>office@worldpatientsalliance.org</u>



Thank You

