



Serving Patients, Improving Healthcare:

The Growing Role of Patient Advocates

INTRODUCTION

“Healthcare is a very strange business: the provider determines the needs of the market. It is, by default, a vulnerable position for a patient.”

– Alexander Kvitashvili, former Minister of Health, Georgia & Ukraine

IN THEORY, the healthcare system should operate with the needs of patients at the center. But in practice, patients’ individual voices can be drowned out by other stakeholders: clinicians, academics, researchers, payers, and life sciences companies.

It is understandable. Life sciences companies are under increasing pressure to drive profits while developing new life-improving treatments. Policymakers and regulators must balance the needs of all stakeholders in approving beneficial treatments and regulating use. Providers and payers are always under pressure to supply equitable care without sacrificing quality. With all those demands, it is easy to overlook patients – though the pressures they face can be truly of life and death.

Enter patient advocates, who act on behalf of those affected by disease to magnify their voices and become active participants in the healthcare system. Advocates may include patients themselves, loved ones, or caregivers – and they speak up for a cause or a group that needs help having its voice heard.

Advocates don't exist only in healthcare. From the American teenagers who created the “March for Our Lives” movement to those promoting the messages of “Time’s Up” and “Me Too” to

address sexual harassment worldwide, activism and advocacy is evolving and gaining importance for a variety of reasons – technological, political, financial, social, and cultural.

Similarly, thanks to their track record of success in impacting change, combined with important trends in healthcare, patient advocates are an increasingly vital and powerful force in promoting awareness and adding value to the development of and access to medicines.

These trends include:

- Life sciences companies are increasing investments to address unmet needs across a broad spectrum of diseases;
- Regulators, payers, HTA bodies, and other policy decision-makers are improving processes for systematic inclusion of patient input throughout the medicine lifecycle; and
- Digital communications are making it easier for patients and advocates to educate themselves, organize, and communicate with each other around the world

As healthcare stakeholders work to incorporate and address patient needs, DKI Health saw the opportunity to help them understand one another,

“You are in a vulnerable position when you’re a patient. Even if you’re very powerful in all other aspects, you’re depending on something to save your life.”

– Jill Bonjean, Muster for Good

“Patient advocacy is a journey. Right now, we’re still outside the system, outside the policy decision-making table...that’s why we continue to protest and demand change...”

– Durhane Wong-Rieger, President & CEO, Canadian Organization for Rare Disorders & Chair, Rare Disease International

and to demonstrate the benefits of collaboration with patient advocates to improve healthcare for all.

To that end, we spoke to international health policymakers, healthcare industry executives, academic experts, and groundbreaking patient advocates. With decades of experience each, they provided insights on patient advocacy: what is being done today that deserves greater attention, what can and should be done, and a vision for the future of patient-centered healthcare.

With these insights, we seek to grow understanding of the role patient advocates serve in improving access to medicines and explore ways that patients can become a true decision-making partner, at the center of the healthcare ecosystem.

A BRIEF HISTORY OF MODERN PATIENT ADVOCACY

WHILE PATIENTS CAN OFTEN BE their own best advocates, through much of healthcare’s history, the patient’s voice was not a priority for others in the health system. In the early 20th century, some progress was made as academics argued for greater consideration of patients, and nurses were empowered to promote patients’ rights. But it was in the 1950’s, during the early days of cancer research and treatment, when patient advocacy took on its current form. In the 1980s and 1990s, patient advocates gained headlines – and life-changing legislation – for people with disabilities or those

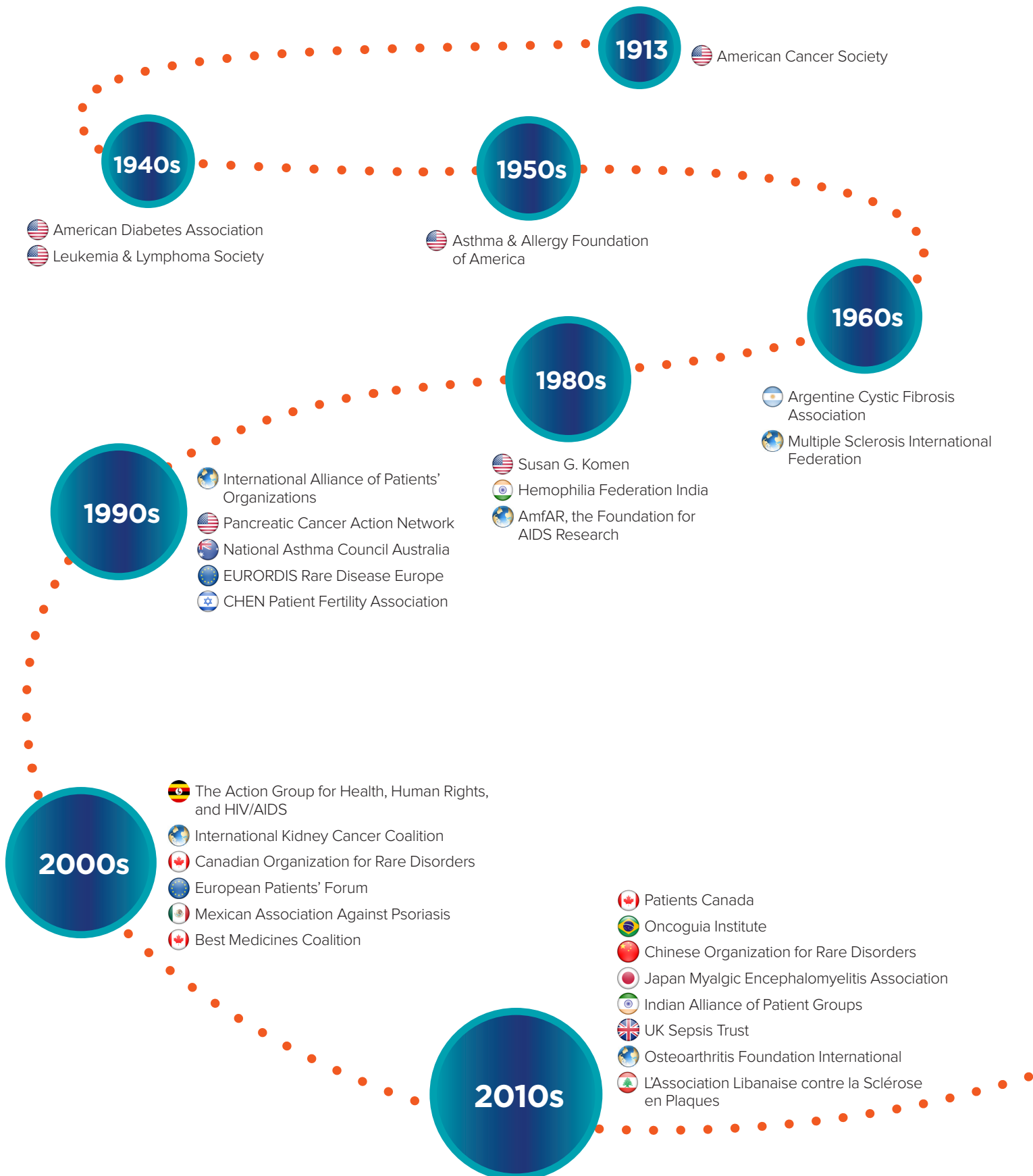
infected with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS). Today, patient advocates may operate through non-profit organizations such as the American Cancer Society, participate in initiatives sponsored by industry organizations, or advocate on an individual basis. Many are motivated by a personal or family connection to a disease, but all work to improve the lives of those affected.

Patient advocates have shaped legislation, research, and the provision of healthcare around the world, saving and improving lives. Perhaps the greatest example came during the HIV/AIDS crisis of the 1980s and 90s. At that time, a 20-year-old infected with HIV could [expect to live](#) only until about age 40.¹ Advocates refused to let patients suffer in silence. In 2001, [The New York Times](#) wrote: “People with HIV and AIDS barged into the councils of the scientific establishment, forcing scientists to consider their views, their desperation, their anguish. It was ‘a new form of constituency advocacy and activism,’ said Dr. Anthony S. Fauci, director of the National Institute of Allergy and Infectious Diseases.”²

Today, a 20-year-old with HIV can [expect to live](#) into their 70s, thanks to increased testing, the development of antiretrovirals, and preventative treatments – all driven by the relentless efforts of patient advocates.³ In doing so, they created a template for action: “a phenomenon,” said Dr. Fauci, “that clearly will be carried forth with other diseases in the 21st century.”⁴ Dr. Fauci’s words echoed in 2016, when Duchenne muscular dystrophy (DMD) patient advocates [won](#) FDA accelerated approval for

SELECT EXAMPLES OF PATIENT ADVOCACY GROUPS AROUND THE WORLD

Patient advocacy as we know it today began in the early 20th century; in recent decades, many advocacy groups have formed, either focused on specific diseases or across a range of diseases, in every region of the world.



The Rise of Patient-Centered Care

“Patient-centered care ... [is] based on deep respect for patients as unique living beings, and the obligation to care for them on their terms. Thus, patients are known as persons in context of their own social worlds, listened to, informed, respected, and involved in their care—and their wishes are honored during their health care journey.”

– *Epstein & Street* ⁵

IN THE LAST DECADE, as the concept of “[patient-centricity](#)” has gained traction,⁶ the pharmaceutical industry has responded, most prominently by naming [Chief Patient Officers](#) to understand and communicate patient views at the highest organizational level.⁷ Sanofi’s [Anne Beal](#) is perhaps the best-known example, holding that position since 2014.⁸ Another is Medtronic’s Chief Patient Officer and VP of Marketing [Louis Diaz](#)⁹. The importance of patient understanding is also seen in the development of [Patient Affairs](#) roles at Pfizer¹⁰ and the Diversity and [Patient Engagement](#) Group at BMS¹¹.

Of the top 10 pharma companies, all have

personnel focused on patients and patient advocates to some degree. While some companies’ efforts are limited to patient support programs, others have developed robust initiatives to involve advocates throughout the product lifecycle, from research and development to commercialization.

Why? As industry blog [eyeforpharma](#) wrote in 2015, “Patient-centricity rose like a phoenix from the ashes of the blockbuster era.”¹² Pharmaceutical strategy was simpler when companies could develop and market a few blockbuster drugs for the masses. Today those are rare, and manufacturers must manage far greater business complexity and nuance in patient need.

eteplirsen – the first for a DMD drug – despite some of the agency’s reviewers expressing doubts of its efficacy.¹³ Patient advocates were instrumental in driving this access to the drug despite insufficient data, largely because DMD is a serious disease with high unmet needs and no other treatment options existed. As required by its accelerated approval, eteplirsen is undergoing a confirmatory [clinical trial](#), with results expected in 2019¹⁴.

Advocates have found other high-profile ways to capture the world’s attention, such as the ALS Association’s *Ice Bucket Challenge* that went viral in 2014. Largely through social media, the cam-

paign increased amyotrophic lateral sclerosis (ALS) awareness [18-fold](#) across the globe¹⁵ and [raised \\$115 million](#) for research to identify genes responsible for ALS within a year of launch.¹⁶

Much of advocates’ work happens quietly but is no less impactful, such as influencing public policy. In a 2017 analysis for *Orphanet Journal of Rare Diseases*, Durhane Wong-Rieger, with other authors, reviewed the [rare-disease plans](#) of 11 nations. They found that “the patient advocacy community is playing a large role in shaping discussions, educating policy makers and driving the political agenda to support national rare disease strategies.”¹⁷

“Today’s patient-advocacy organizations are more sophisticated and knowledgeable. These groups not only provide patient-friendly disease awareness, education, and support; they can also participate at a higher level in the healthcare process and engage in drug development and health technology assessment.”

– Associate Director, Global Advocacy, Top 20 Pharma Company

FROM ADVOCATE TO INFLUENCER - CURRENT STATE OF PATIENT ADVOCACY

A “PATIENT ADVOCACY ORGANIZATION” can be individuals working in their spare time, up to large non-governmental organizations (NGOs) rivaling multinational corporations in size and scope. They may raise disease awareness, seek to improve diagnosis, increase funds for research, advocate for better legislation, help patients and their loved ones navigate treatment, educate healthcare companies on patient need – or do any combination of these activities. Increasingly, they are also banding together across disease states and geographies. For example, EURORDIS established [RareConnect](#), which is an online network of rare-disease communities that provides moderators and translation services in ten languages to empower patients around the world.^{18,19}

Patient advocates are influencers, and the most successful are passionate and driven, usually with a powerful personal connection to the condition. Whether the diagnosis came to them or their loved one, their motivation sparked, and their life changed. For example, [Durhane Wong-Rieger](#), president of the Canadian Association for Rare Diseases, became an advocate when her two children were diagnosed with rare diseases.²⁰ [Paula Kim](#) lost her father to pancreatic cancer in 1998, but

the connections she built while helping him led her to co-found the Pancreatic Cancer Action Network (PanCAN).²¹

This personal emotional involvement can make advocates unusually passionate entrepreneurs, but can also create difficulties in evolving from a “one-person show” into a successful organization. It must be done deliberately, building a team with complementary skill sets while managing the finances of a growing operation. Building a succession plan, critical for longevity, should also be a priority.

While an early-stage advocacy effort may rely on volunteer and part-time staff, they must eventually scale up to make ongoing meaningful impact. As Alexander (Sandro) Kvitashvili, the former Minister of Health in Georgia and Ukraine, said, “I appreciate volunteering, but I don’t hire volunteers.” Advocate leaders agree. “It’s hard to be tenacious, even under the best of circumstances,” said Paula Kim, founder/CEO of TRAC and co-founder of PanCAN.

Fortunately, advocates can tap technology as a force multiplier to access global knowledge and networks. The internet likewise empowers patients beyond what was possible or even imaginable previously. Social media will continue to facilitate rapid and massive information sharing between patients, advocates, and industry/regulatory stakeholders.

ADVOCACY MAKES A DIFFERENCE

KVITASHVILI ACKNOWLEDGES that as a health policymaker, it is incredibly difficult to say no to vocal patient advocates – and even more so if saying yes provides important drugs for children. Speaking of his time in Georgia and Ukraine, he stated, “We had to find the money...we couldn’t only finance 30% of a life-saving drug...we would go to Ministry of Finance and try to find money from other budget streams.”

“You can see the power of patient-advocacy organizations in action in the initiatives that governments around the world are supporting to address previously “invisible” diseases – whether it’s in a rare disease (or in other disease areas). The noise that patient advocates make is directly responsible for getting prioritization and investment in their diseases.”

- Director, Public Policy & Advocacy, Top 5 Pharma Company

Key Attributes for Successful Advocacy

“Advocacy is telling a story – mobilizing people for action – inspiring people – getting policymakers to listen. It’s getting people to do the right thing.”

- Paula Kim, co-founder, PanCAN; founder and CEO, Translating Research Across Communities (TRAC)

SUCCESSFUL PATIENT ADVOCATES combine passion for an often-personal mission and an entrepreneurial spirit with professional savvy in order to influence some of the world’s largest organizations. Attributes they frequently demonstrate include:

- Self-motivation – desire to seek information, learn, self-instruct
- Authenticity – transparency, integrity, and clarity of purpose
- Passion – belief in the importance of the cause
- Persistence – resilience in the face of setbacks
- Positivity – confidence in the eventual success of the cause
- Resourcefulness – willingness to seek multiple and sometimes untried paths
- Networked – meeting and connecting with many well-placed individuals
- Visionary – remaining focused on a lofty end goal

Another attribute that helps advocacy succeed is a marquee name: a recognized spokesperson can open doors and generate media raising the cause’s profile. For example, Lou Gehrig²², Michael J. Fox²³, and Magic Johnson²⁴ have all successfully brought their respective diseases into public consciousness – ALS, Parkinson’s, and HIV/AIDS – respectively.

Caregivers: “Unsung Heroes of Health”

AS FORMER FIRST LADY Rosalynn Carter said, “there are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.” Many of us will hold more than one of those roles in our lives.

Most patient advocates began their involvement as either patients or caregivers, managing a diagnosis that was often unexpected and life-altering. But among caregivers, there is what Meagan Bates Perry, Associate Director of Patient Advocacy at EMD Serono, calls a “self-identification crisis”. Around the world, advocates and other organizations face the added hurdle of trying to reach people who don’t realize that they are part of a group for whom help is offered.

To help increase the global discussion of caregiving and create opportunities for caregiver support, EMD Serono spearheaded the creation of [Embracing Carers](#)²⁵ in 2017, a coalition of nine caregiver organizations from around the world.

Patient advocacy around the world is changing healthcare every day in important ways, including:

- **Better treatments:** In 2017, EMA sought [patient input](#) when providing scientific advice to companies submitting medicines for review and approval. Of 90 responses by the EMA, patient voice impacted 39, and led to EMA changing the final advice given in 24.²⁶
- **Policy development:** In 2018, the Asia-Pacific Economic Cooperation’s Life Sciences Innovation Forum (APEC LSIF) instituted a [10-point plan](#) for improving the lives of those with rare diseases in their 21 member nations.²⁷
- **Awareness, prevention, and diagnosis:** In 1985, the American Cancer Society (with industry partners) created National Breast Cancer Awareness Month to promote early detection. Since that time, mammogram rates have more than [tripled](#).²⁸
- **Access to treatment:** The [World Federation of Hemophilia](#) (WFH) annually provides treatment to tens of thousands of patients in more than 90 countries where access is lacking.²⁹

THE FUTURE OF PATIENT ADVOCACY

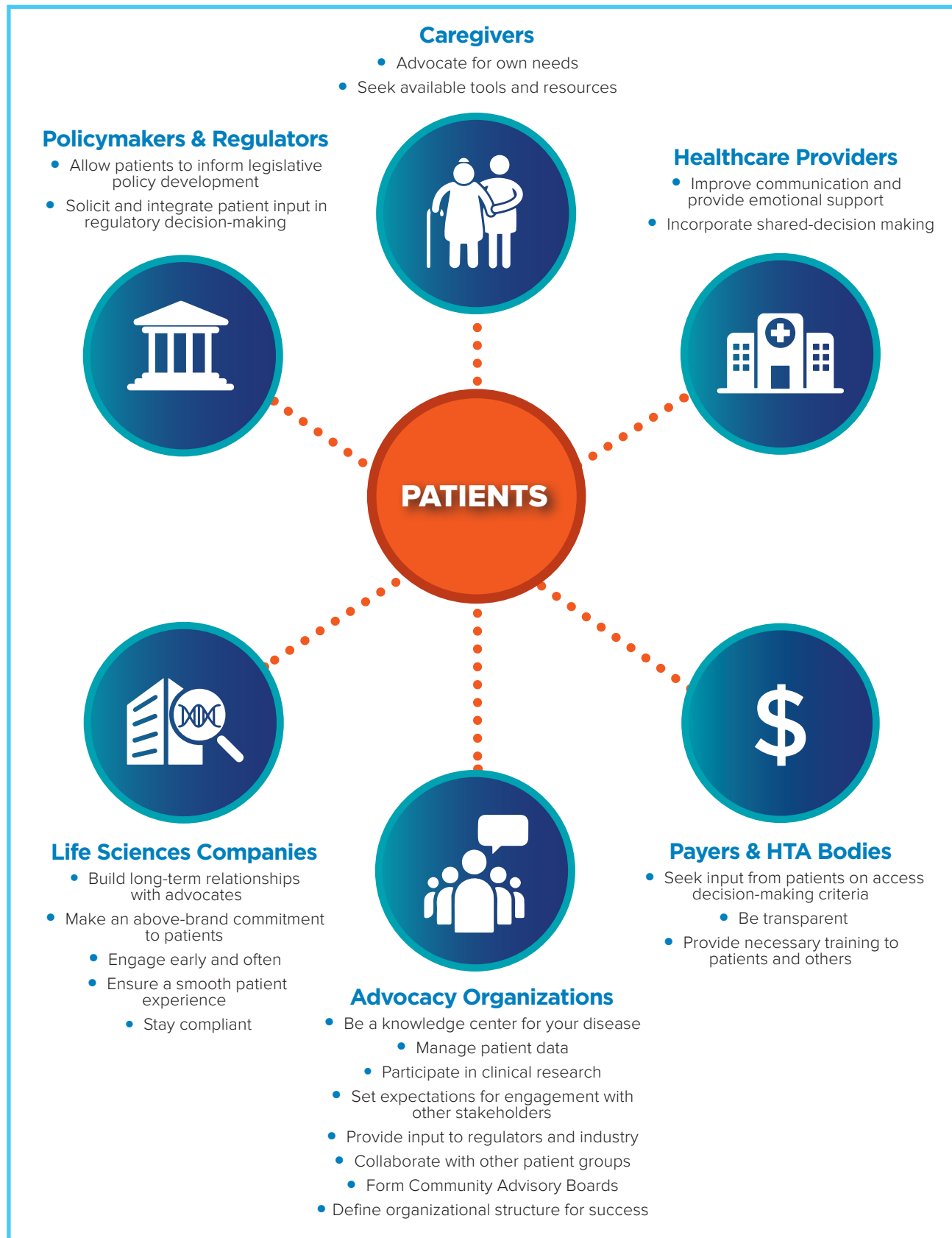
ALL THE STAKEHOLDERS we spoke with agreed that greater involvement from informed patients and advocates can benefit the future of medicine. They also agreed that we’re not quite there yet – too often, patient advocates are still treated as

“We want a world where we don’t have patient advocates, because that means we’re on the outside, not part of the system. We need to change that. If you’re part of the process, you don’t have to be an advocate: you’re a partner.”

– Durhane Wong-Rieger, President & CEO, Canadian Organization for Rare Disorders & Chair, Rare Disease International

DKI HEALTH PERSPECTIVES – A CALL TO ACTION TO ADVANCE PATIENT-CENTRICITY

To keep patients at the center of the healthcare ecosystem,
our research suggests important roles for all key stakeholders:



Advocacy Organizations

- Be a knowledge center (“information hub”) for your disease area(s)
- Develop skills to work adeptly in the data economy – collect, analyze, interpret, and manage data including:
 - patient data
 - clinical research
 - health economics studies
- Seek and participate in clinical research and studies
- Set clear expectations for engagement with other stakeholders, including industry
- Engage with regulators and provide input into the drug development, approval, and reimbursement processes
- Collaborate with organizations across disease areas and regions to share best practices and key learnings; build advocacy capacity; and magnify the patient voice
- Form disease-specific Community Advisory Boards to advise researchers, policymakers, and other stakeholders such as those for:
 - [HIV](#)³⁰
 - [rare disease](#)³¹
- Understand the healthcare system in which the organization operates, and structure accordingly to best achieve goals (this may include staffing, partnering, succession planning, messaging, and other key topics)

Caregivers

- Advocate for caregivers’ own needs as they pursue their vital and often challenging role in caring for patients
- Seek tools and resources provided by healthcare providers, payers, and others that help improve caregivers’ own quality of life

Healthcare Providers

- Improve communication and emotional support for patients throughout diagnosis and treatment, for example:
 - Physicians can incorporate psychosocial support when informing patients and their loved ones of a difficult illness
 - Treatment programs can include nurse educators, who help patients with medication adherence, disease education, emotional support and other treatment concerns
- Incorporate shared decision-making with patients and caregivers in selecting tests, treatments and care plans based on clinical evidence, balancing risks and expected outcomes with patient preferences and values³²

Life Sciences Companies

- Build long-term relationships with patients and advocates (starting in the early stages of research and development, as [recommended](#) by experts³³) based on a common vision to address unmet needs
- Make an above-brand commitment to patient advocacy and engagement, ensuring continued relationships with advocates even when setbacks occur such as drug failures or budget cuts
- Develop and adhere to a clear set of guidelines for engagement with patients, staying compliant while ensuring that the engagement process is smooth, consistent, and beneficial for participants
 - Novartis' [Commitment to Patients and Caregivers](#) is a good model for principles guiding engagement with patients and advocates³⁴

Payers & Health Technology Assessment (HTA) bodies

- Seek input from patient advocates in payer and HTA decision-making processes on access to treatments, support programs, and preventative care
- Be transparent in your decision-making processes
- Support the training and development for patients and advocates to help them provide useful input (as payer/HTA processes can be somewhat arcane to outsiders)
 - [Brian O'Rourke](#), chair of the International Network of the Agencies for Health Technology Assessment, may have said it best: "If you're not involving patients, you're not doing HTA! It's that simple. ... It is difficult to conceive of HTA being conducted in a meaningful way in the 21st century without the involvement of patients."³⁵

Policymakers & Regulators

- Align with advocates to better understand the ongoing needs of patients and caregivers, and inform policy development accordingly
 - Studies have [demonstrated](#) the positive impact that healthcare advocacy can have on legislative decisions.³⁶
- Continue soliciting and integrating patient input, as the FDA and EMA have done in recent years
 - The FDA's [Patient Affairs Staff](#) was established in 2017 within the Office of the Commissioner to work across product centers to support patient engagement efforts.³⁷
 - The EMA established their Public Engagement Department in 2014, which works toward "systematic inclusion of patient input along [the] medicine lifecycle." Over the last decade, EMA has [multiplied](#) its annual occurrences of patient/consumer involvement five-fold.³⁸

The Role of Advocates in Managing Patient Data

“Patient-centricity seems like common sense – a world in which patients own their own data and can access it - but it isn’t that way right now.”

- Kamal Obbad, co-founder, Nebula Genomics

AS TECHNOLOGY INCREASINGLY MERGES with healthcare, an important paradigm shift relates to the collection, ownership, and management of patient data.

Medical records and clinical trial data are captured electronically, and consumers are increasingly measuring and tracking their own health with digital tools – producing many times the amount of health information than ever before. The implications are vast: potential for understanding disease, how we treat it, and how we live with it. Life sciences companies can reduce development times and costs while better targeting patient populations. Providers can use biomarkers to personalize treatment plans that are most effective for each patient. Payers can reimburse for outcomes and value.

Here too, advocates can play a critical role. Patients are generally willing to share their health data with industry partners in hopes of improving treatments; however, concerns related to privacy, security, and access (to one’s own data) abound. Patient advocacy organizations can become the de-facto managers of disease-specific registries: obtaining patient consent; safeguarding sensitive information; providing researchers with high-

quality data; and ensuring patients can manage their own information across companies and over time.

EURORDIS provides a practical example of how to lead such an initiative – through a robust surveys program, advocates across many countries actively create and analyze databases, recording the perspectives of various rare disease patients and caregivers. These databases with other patient registries are valuable resources for all stakeholders.

However, when generalizing population-based data, there is a risk of losing sight of the needs of any individual patient. Advocates and advocacy organizations must understand the effects of data analytics to ensure that they are aware of industry’s intentions for patient data utilization and to determine if that data usage is in-line with their objectives and the needs of their members.

Advocates who understand the increasing importance of data, and who can become conversant in data analytics and associated technologies, will find their insights grow even more valuable. In healthcare, as in many other industries, data is currency.

“vendors” and engagement can be transactional, with industry providing grants for specific initiatives but not always building long-term relationships or seeking collaborative partnerships.

But this may be changing. One industry executive we spoke with, in charge of public policy and advocacy at a top-5 pharma, stated: “We are continually impressed with how experienced, educated, and impactful the patient advocacy organizations are.” The team was inspired to engage with the patient advocates in a dynamic manner, sharing decision-making about potential projects to work on together.

In the future, as stakeholders continue to benefit from including informed and educated patient advocates in decision-making across all stages of the drug development cycle – from early clinical trials and appropriate endpoint selections to funding and reimbursement decisions – patients will likely emerge as true thought leaders – experts in their own disease, providing essential insight in identifying unmet needs, driving recognition and

awareness, supporting the development of better policies and treatments, and improving access to new medicines.

CONCLUSIONS

AS HEALTHCARE EVOLVES, so too will the role of patient advocates. Demand for their insights will likely increase as policy makers increasingly seek patient voice in decision-making. Their value will grow as life sciences companies tap their understanding early and often in the development of drugs, devices, tools and services. New technologies and channels of communication will accelerate important patient initiatives such as disease awareness, education and support. As the healthcare system’s emphasis on the patient at center grows, we believe that wise stakeholders will deepen their relationships with patient advocates, and recommend that those stakeholders who have not should begin to do so right away.

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