

# ELLA BALASA

Patient Expert and Advocacy Consultant

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## WEBSITE

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## PROFILE

As a healthcare consultant working with industry, non-profit patient organizations, and other healthcare companies and initiatives, I have a passion for utilizing my patient voice, science understanding, and business perspective to bridge communication and partnership across the healthcare ecosystem and improve patient health.

## PROFESSIONAL EXPERIENCE

- ❖ **Patient Engagement and Healthcare Consultancy** .....  
Drawing on my lived experience as a rare disease patient combined with my work in the advocacy field has allowed me to understand and develop successful methods of patient engagement. As an advisor and collaborator, I incorporate the patient voice and feedback into projects to foster meaningful patient connections. Below are the consulting roles and activities I am involved with:
  - ❖ **Plain Language Summary Reviewer, Future Science Group** ..... Nov 2023 — Present
    - Review material specifically intended for a patient/general public audience to enhance the quality of the PLS by assessing the readability and understanding.
  - ❖ **Patient Expert, EUPATI** ..... Oct 2023 — Present
    - Completed a comprehensive training program learning the lifecycle of medicine research and development to provide advice to industry, regulators and HTA bodies and engage in producing and participating in webinars, workshops, and multistakeholder research committees.
  - ❖ **Rare Disease Advisory Panel, PCORI** ..... Sep 2023 — Present
    - Appointed to support the guidance and creation of evidence based information on comparative effectiveness research that is guided by patients, caregivers, and the broader health community.
  - ❖ **Patient Advocate Panel, ZS Consulting** ..... May 2023 — Present
    - Sharing experience and insights at ZS meetings acting as an advisor to provide input on content such as thought-leadership pieces, proposals, patient-facing discussion guides, surveys, and participating in market research opportunities- focus groups and co-creation
  - ❖ **Patient Advisory Council , Parexel** ..... Mar 2023 — Present
    - Inform the patient perspectives of priorities and issues in connection with the conduct of clinical studies for sponsors.
  - ❖ **CF Patient Advisory Board, DKBmed** ..... Jun 2022 — Present
    - Create video and presentation content for the CF resource library on patient information as well as guide the strategy on gaps and needs in education and awareness.
  - ❖ **Non-profit Advisory Board Coordinator, Cystinosis Research Network** ..... Jun 2022 — Present
    - Provide guidance to the Adult Leadership Advisory board comprised of patients living with cystinosis to develop resources and support to the broader community through the creation of webinars, newsletters, podcast, and social media education and community building content.
  - ❖ **Content Expert, Questex/Fierce Pharma** ..... Jan 2022 — Present

- Develop well researched industry facing materials (Info-graphics, white papers, articles) to provide information and promotional support of healthcare products and services across the landscape.

❖ **Patient Insights Board, Medidata** ..... May 2021 — Present

- Communicate key learnings from my personal health experiences and observations of patient community bringing patient centricity throughout development and optimization of products.
- As inform cross-functional (clinical, and commercial) internal team strategies

❖ **Clinical Editor, Lyfebulb** ..... Jul 2021 — Jul 2023

- Strategize and develop patient facing clinical trial educational materials, newsletters, and social media content to increase health literacy support for patient populations across various diseases.

❖ **Patient Contributor, CISCRP** ..... Mar 2021 — Present

- Review lay clinical trial summaries and materials to assess the readability and relatability to educate and inform patient communities.
- Contribute to advisory boards and patient feedback initiatives developing tools for industry utilization

❖ **Co-Creation Council, Genetech** ..... Jan 2021 — Present

- Optimize feedback in marketing and clinical patient materials (consents, drug assistance program documents, etc) to assure and enhance initiatives are patient-centered and inclusive of diverse patient representation.

❖ **Patient Leadership Council and Content Contributor, Health Union** ..... May 2021 — Present

- Innovate patient advocacy written and video content to increase patient empowerment and health knowledge in the cystic fibrosis community

❖ **Patient Advisor, Cystic Fibrosis Foundation** ..... Dec 2018 — Present

- Protocol Review Committee: Evaluate clinical trial programs across the dimensions of scientific merit, study design, and feasibility.
- Infection Research Initiative Steering Committee Member: Advise on infection research portfolio priorities - gaps, opportunities, and priorities.

## EDUCATION

❖ **Virginia Commonwealth University** ..... 2010 — 2014

*Bachelor of Science in Biology*

Richmond, VA

## SKILLS

Creative problem solving, team brainstorming, and analytical thinking

Wix, Mailchimp, WordPress, Canva, Microsoft Office, G Suite

Communications and Public Speaking

Social media & content creation

## VOLUNTEER PATIENT ROLES

❖ **Patient Engagement Taskforce Member** ..... Jul 2023

*International Society for Medical Publication Professionals (ISMPP)*

- Develop a framework for encouraging more patient engagement publications by raising awareness to patients to empower them and present an evidence base for patient involvement to secure resources and budget from within industry.

❖ **Patient Editorial Board Member** ..... Oct 2021 — Present

*Springer Pulmonary Therapy Journal*

- Review and edit clinical trial lay summaries for optimal patient and healthcare ecosystem wide applicability,

❖ **Ambassador and Delegate** ..... Dec 2020 — Present

*Patients Rising*

- Serve as a contact and resource for patient advocates and develop my own personal advocacy skills through the leadership and collaborations as part of Ambassador Program and Delegate Program increasing my knowledge of healthcare legislation.

❖ **Patient Reviewer** ..... Nov 2019 — Dec 2021

*The British Medical Journal (BMJ)*

- Review journal submissions to produce content of relevance to patient-centeredness in research design and reporting.

❖ **Young Professional Leadership Council (YPLC)** ..... Jul 2018 — Present

*Cystic Fibrosis Foundation Virginia Chapter*

- Raise awareness and funds by sharing experience through speaking engagements and newsletters and organize and facilitate networking and fundraising events.

## SPEAKING AND PRESENTATIONS

❖ **Scope Summit** ..... Feb 2024

Panel Topic: "The Intersection of Patient Advocacy and Clinical Operations in Enhancing Patient and Community Engagement" Orlando

❖ **Adaptive Phage Therapeutics** ..... Feb 2024

Presentation Topic: "A CF Story - Combatting AMR Infections with Phage" Virtual

❖ **BioMerieux** ..... Jan 2024

Presentation Topic: Patient Testimonial Cancún

❖ **Medidata NEXT** ..... Nov 2023

Panel Topic: "Explore The Possibilities With Patient Payments" New York City

❖ **Mobile Technologies in Clinical Trials** ..... Sep 2023

Conference co-chair Boston

❖ **World AMR Congress** ..... Sep 2023

Panel Topic: "Overcoming Resistance: Policy Change and Data Driven Communications" Philadelphia

❖ **One Rare Experience** ..... Jul 2023

Presentation Topic: "A Journey from Healthcare Experiences to Healthcare Consulting" Boston

❖ **Healthcare Improvement Trailblazers Summit** ..... Jun 2023

Panel Topic: "Cross-Stakeholder Perspectives on Healthcare Improvement: Potential, Barriers, and Trends" Washington, D.C.

❖ **Outsourcing Clinical Trials** ..... May 2023

Presentation Topic: "Strengthening Patient Relationships to Enhance the Therapeutic Development Process" Philadelphia

❖ **International Society for Medical Publication Professionals** ..... Apr 2023

Panel Topic: "Personalize patient engagement by integrating your innovation and digital strategies" Washington, D.C.

❖ **Genentech** ..... Mar 2023

Presentation Topic: Patient testimonial San Francisco

❖ **Reuters Pharma USA** ..... Mar 2023

Panel Topic: "Improving Patient Access for Rare Disease Indications" Philadelphia

❖ **Patients as Partners** ..... Mar 2023

Panel Topic: "Applying Health Literacy Principles to Enhance Clinical Research and Participation in Trials" Washington, D.C.

❖ **ErgoMed** ..... Nov 2022

Virtual



Presentation Topic: "Perspectives on Patient-Focused Drug Development in Rare Disease"

<b>❖ International Pharmaceutical Federation</b> .....	Oct 2022
Presentation Topic: "Antimicrobial Stewardship: Communities in action"	Virtual
<b>❖ Reuters</b> .....	Oct 2022
Panel Topic: "Personalize patient engagement by integrating your innovation and digital strategies"	Virtual
<b>❖ Admedicum LinkedIn Live Webinar</b> .....	Sep 2022
Presentation Topic: "Patient-inclusion in clinical trial design"	Virtual
<b>❖ CF Research Institute National CF Education Conference</b> .....	Aug 2022
Panel Topic: "Phage Therapy: A Panel Discussion with Phage Therapy Recipients and Clinician"	Virtual
<b>❖ Cystic Fibrosis Foundation Volunteer Leadership Conference</b> .....	Jul 2022
Panel Topic: "Advocacy in Action: Addressing Antibiotic-Resistant Infections"	Virtual
<b>❖ World Orphan Drug Congress</b> .....	Jul 2022
Panel Topic: "Transformative digital health strategies for rare disease decentralized clinical trials"	Boston
<b>❖ DIA Global Annual Meeting</b> .....	Jun 2022
Panel Topic: "Preparing for the Future of Research and Development: 10-Years of Multi-stakeholder Innovation, Collaboration, and Transformation"	Chicago
<b>❖ Rare Disease Innovation &amp; Partnering Summit 2022</b> .....	May 2022
Fireside chat Topic: "Strengthening Patient Relationships Authentically to Enhance the Therapeutic Development Process"	Boston
<b>❖ MAGI Clinical research Conference</b> .....	May 2022
Presentation Topic: "Optimally Supporting Patients Throughout Trial Recruitment and Participation"	Boston
<b>❖ Marcus Evans Evolution Summit</b> .....	Mar 2022
Presentation Topic: "Strengthening patient relationships authentically to enhance the therapeutic development process"	Los Angeles
<b>❖ Financial Times</b> .....	Mar 2022
Panel Topic: "Evaluating the Success of Decentralised Clinical Trials"	Virtual
<b>❖ Open Health</b> .....	Mar 2022
Panel Topic: "Effectively articulating burden for future health technology assessments"	Virtual
<b>❖ Journal of Health Design</b> .....	Jan 2022
Podcast Topic: Building strong relationships between physician and patients on the pillars of openness, empathy, and a mutual effort for improvement in healthcare outcomes	Virtual
<b>❖ Biotech Atelier</b> .....	Nov 2021
Presentation Topic: How I became a better advocate - The Intersection of a Science Background and Patient Advocacy	Virtual
<b>❖ DKBmed</b> .....	Oct 2021
Panel Topic: eCystic Fibrosis Review Advocacy Chat	Virtual
<b>❖ Bayer - Town Hall</b> .....	Jun 2021
Conversation Topic: Product platforms in remote clinical trials	Virtual
<b>❖ Open Health</b> .....	May 2021
Panel Topic: Mobilizing pathways to accommodate new transformative treatments - using CF as a case study	Virtual

❖ <b>Sepsis Tech and Innovation Conference</b> .....	May 2021
Panel Topic: Innovation and Challenges in the Fight Against AMR	Virtual
❖ <b>New York Bio Patient Engagement Summit</b> .....	Apr 2021
Panel Topic: Patient Advocacy Experiences	Virtual
❖ <b>Patients As Partners Conference</b> .....	Apr 2021
Panel Topic: Patient Perspectives on How R&D Organizations can Better Prepare Patients for their Clinical Trials	Virtual
❖ <b>Precision Medicine Forum Patient Week</b> .....	Mar 2021
Panel Topic: Are Patients the Missing Part of the Drug Development Puzzle?	Virtual
❖ <b>Pharma &amp; Patient USA Conference</b> .....	Dec 2020
Roundtable Topic: Empower patients to enrich your participation strategy	Virtual
❖ <b>Presidential Advisory Council on Combating Antibiotic-Resistant Bacteria (PACCARB)</b> .....	Sep 2020
Public Meeting Topic: Intersection of COVID-19 and AMR	Virtual
❖ <b>Biotech Atelier Conference</b> .....	Sep 2020
Presentation Topic: "The Value of the Patient Experience"	Virtual
❖ <b>Infectious Disease Society of America (IDSA)</b> .....	Aug 2020
Congressional Meeting Topic: Antimicrobial Resistance and COVID-19 - How Congress Can Address Converging Crises	Virtual
❖ <b>Corbus Pharmaceuticals and TranslateBio</b> .....	May 2020
Cystic Fibrosis Awareness Presentation: "This Lung Life"	Virtual
❖ <b>FDA Rare Disease Day 2020</b> .....	Feb 2020
Panel Topic: Supporting the Future of Rare Disease Product Development	Washington, D.C.
❖ <b>Milken Institute Future of Health Summit</b> .....	Oct 2019
Panel Topic: Race Against Resistance: Overcoming Antibiotic Market Failures	Washington, D.C.

## PUBLICATIONS

❖ <b>Clinical Leader</b> .....	Jan 2024
"Patient Engagement Needs More Benefit Analysis, Fewer Theoretical Conversations"	
❖ <b>Clinical Trials for All</b> .....	Aug 2023
"My Journey with Cystic Fibrosis"	
❖ <b>Society for Participatory Medicine</b> .....	Aug 2022
"The Keys to Good Relationships With Your Care Teams"	
❖ <b>BMJ Open Quality</b> .....	May 2022
"Cystic fibrosis learning network telehealth innovation lab during the COVID-19 pandemic: a success QI story for interdisciplinary care and agenda setting"	
❖ <b>INQUIRY Journal</b> .....	Mar 2022
"Coming Full Circle: Reflections and Inspirations from a Cystic Fibrosis Patient Scientist Panel"	
❖ <b>"Chronically Empowered"</b> .....	Oct 2021
Contributor to book highlighting the stories of 65 advocates' stories of resilience, determination, and strength to bring awareness and understanding of many chronic illnesses.	

- ❖ **PM360** ..... Sep 2021  
 "Key Questions about Patient Experience in 2021"
- ❖ **International Journal of General Medicine** ..... Jul 2021  
 "Airway Clearance Therapy in Cystic Fibrosis Patients"
- ❖ **The British Medical Journal** ..... Feb 2021  
 "Ella Balasa: Antibiotic resistance, chronic disease, and covid-19—a triple threat"
- ❖ **Springer Pulmonary Therapy Journal** ..... Oct 2020  
 "The Lung Life of a cystic fibrosis patient: A Patient and Physician Perspective"
- ❖ **HuffPost** ..... Apr 2019  
 "I Inhaled Viruses As A Last-Ditch Effort To Fight A Drug-Resistant Bacterial Infection."
- ❖ **STAT News** ..... Nov 2018  
 "One number keeps me from taking part in cystic fibrosis trials. That's wrong."
- ❖ **MedPage Today** ..... Oct 2018  
 "I'm Drowning: A researcher-patient's plea for broader inclusion in cystic fibrosis trials."