



Letter from Scientists and Clinicians on the Breakthrough Prize for publication in the Boston Globe

On Saturday the annual Breakthrough Prize, dubbed the ‘Oscars of Science’, will hold its glitzy awards ceremony in LA. This year’s Life Sciences Prize is being awarded to three scientists - Sabine Hadida, Paul Negulescu and Fredrick Van Goor of Vertex Pharmaceuticals, for their role in creating a ‘miracle’ class of cystic fibrosis drug, that changes the disease from an early death sentence to a manageable condition. The awardees deserve this recognition, and we congratulate and thank them for their groundbreaking work.

However, the celebration of their achievements is overshadowed by the reality that this life-saving innovation is only available to people in wealthy countries due to the high cost set by Vertex. For the many people with CF living in poorer countries, Trikafta is simply unaffordable at current listed prices which in the US is \$326,000 per person per year.

The estimated production cost of Trikafta is as low as \$6000 per patient per year which suggests that the pricing of Trikafta is driven more by maximising profits than the wellbeing of CF communities worldwide. Vertex is aggressively defending its global monopoly and fighting the efforts of CF communities in poor countries to secure access to affordable generic versions of their medicines.

The lack of access to this miracle drug in poor countries, based on affordability, is a stark reminder of the inequity in healthcare innovations across the world. As CF scientists and clinicians from across the globe, we are standing with the CF community to call on the Breakthrough Prize organisers and awardees to reflect on global inequity and to consider who is benefiting from their groundbreaking innovation and profits. We urge them to use their positions and influence to support calls to make Trikafta, and other innovative life-saving drugs, affordable to everyone who stands to benefit.

| Name | Position | Institution |
|--|--|---|
| Dr Ziska Adams | MD | Robertson Hospital, South Africa |
| Professor Dodo Agladze | MD National monitoring program for CF | LTD Medical Genetics and Laboratory Diagnostic Center |
| Professor Margarida D. Amaral | Group Leader of CF Research Group | Faculty of Sciences, University of Lisbon, Portugal |
| Dr Jennifer L Bass | MD, Pediatrician | |
| Catherine Brown | Specialist Physiotherapist in Cystic Fibrosis | West Midlands Adult CF Centre, UK |
| Professor Nazan Cobanoglu | MD | Division of Pediatric Pulmonology, Department of Pediatrics, Faculty of Medicine, Ankara University, Turkey |
| Dr Arnold Engelbrecht Worcester Provincial Hospital, Western Cape, South Africa. | Paediatrician | Worcester Provincial Hospital, Western Cape, South Africa |
| Dr Marelize Fischer-Gerber | General Practitioner | South Africa |
| Dr Elizabeth Gibb | MD, CF Centre Director | University of California, San Francisco, US |
| Professor Tanja Gonska | Associated Professor | Hospital for Sick Children, Toronto, Canada |
| Dr Wayne Gordon | Previously Medical Officer | Adult Cystic Fibrosis Clinic, Charlotte Maxeke Academic Hospital, Johannesburg, South Africa |
| Dr Jonathan Guo | Academic Foundation Doctor | The Hillingdon Hospitals NHS Foundation Trust, UK |
| Dr Satenik Harutyunyan | MD | Yerevan State Medical University, Republican CF Center, Muratsan University Hospital, Armenia |
| Dr Saurav Jain | Assistant Professor and consultant Pediatric Pulmonologist | St.Johns Medical College and Hospital,Bangalore,India |
| Professor Bulent Karadag | MD, Head of the Division of Pediatric Pulmonology, | Marmara University Faculty of Medicine, İstanbul, Turkey |

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| Professor Nataliya Kashirskaya | Laboratory of Clinical Genetics (Cystic Fibrosis Group) | Research Centre for Medical Genetics, Moscow, Russia |
| Dr. Prawin Kumar | Additional Professor, Pediatrics | AIIMS Jodhpur, India |
| Professor Meghan McGarry | MD, Pediatric Pulmonary Doctor, Cystic Fibrosis & Health Equity Researcher, | University of California, San Francisco, US |
| Professor Brenda Morrow | Professor in Paediatrics and Child Health | University of Cape Town, South Africa |
| Dr Samya Z Nasr | MD, Professor of Pediatrics, CF Center Director | C.S. Mott Children's Hospital, University of Michigan Health |
| Professor Brian P. O'Sullivan, | MD, Professor of Pediatrics | Geisel School of Medicine Pediatric Pulmonology, Director NH Cystic Fibrosis Center, Dartmouth-Hitchcock Medical Center |
| Professor Mark S. Pian, MD | MD, Professor Emeritus, Pediatrics | University of California San Diego School of Medicine, US |
| Professor Paul M. Quinton | Professor of Pediatrics, Emeritus | University of California, San Diego, School of Medicine, US |
| Violeta Railean | PhD student | BioSystems & Integrative Sciences Institute, BioISI, Portugal |
| Cláudia S Rodrigues | PhD student | BioSystems & Integrative Sciences Institute, BioISI, Portugal |
| Dr Jack K. Sharp | MD | Nunnelee Pediatric Subspecialty Clinic, UNC Health-Children's, Wilmington, North Carolina, US |
| Dr Eric C Walter | MD, MSc | Portland, OR, US |
| Professor Marco Zampoli | Associate Professor In Paediatrics. University of Cape Town, SA | Head of the Paediatric Cystic Fibrosis clinic, Red Cross War Memorial Children's Hospital |
| Professor Edith Zemanick, MD | MD, Professor of Pediatrics | University of Colorado School of Medicine |