

INFLUENTIAL STAKEHOLDERS in RARE DISEASE POLICY



PATIENT Voices

- NORD • EVERYLIFE
- FARA • MDA • CYSTIC FIBROSIS
- C-PATH • RDDC
- GLOBAL GENES • PIPC
- UNDIAGNOSED DISEASE NETWORK FOUNDATION
- AMERICAN ASSOCIATION on INTELLECTUAL & DEVELOPMENTAL DISABILITIES
- NATIONAL PARTNERSHIP for WOMEN & FAMILIES



RESEARCH

- RARE-X • ACADEMIC • NIH
- NATIONAL MINORITY QUALITY FORUM • PICNIC HEALTH
- REGAN UDALL • PCORI
- ARPAH/H • TED • CZI



CARE GIVERS



CLINICIANS/ PROVIDERS

- AMERICAN SOCIETY of GENE & CELL THERAPY
- AAU
- NSGC
- SPED
- AAFP
- AMERICAN SOCIETY of HUMAN GENETICS
- NASP
- KEY GENETICIST
- FAITH GROUPS
- AAMC
- AMERICAN SOCIETY of GENETIC COUNSELORS
- SOCIAL WORKERS
- FUNCTIONAL MEDICINE
- OB/GYN
- CENTERS of EXCELLENCE



COMMUNICATIONS & NETWORKING

- ACADEMIC PUBLICATIONS
- CONFERENCES • META
- LINKEDIN • TIKTOK

REGULATORY



- FDA • CDRH • CBER
- RARE DISEASE HUB • CDC
- CDER • OSTP • CMS
- DPC

HEALTH SYSTEMS



- CHILDREN'S HOSPITAL ASSOCIATION
- AHA



PAYERS

- PRIVATE PAYER HEALTH INSURANCE
- ICER
- EMPLOYERS
- PCMA
- PUBLIC PAYER (CMS)
- AHID
- SOCIAL SECURITY DISABILITY



TECH SOLUTIONS

- Dx COMPANIES
- AI-CHAI
- DATA COMPANIES, eg AI EHR



POLICY MAKERS

- FEDERAL POLICY MAKERS
- RARE DISEASE CAUCUS
- NATIONAL ASSOCIATION of STATE MEDICAID DIRECTORS
- NCSL • NGA



INTERNATIONAL

- WHO • EMA • ICH



DEVELOPERS

- BIO • ARM
- PHARMA COMPANIES
- INVESTORS

MANY of THESE ORGANIZATIONS PLAY MORE THAN ONE ROLE... WE HAVE ORGANIZED THEM BY PRIMARY CATEGORY

