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21st Century Cures Act:
Interoperability, Information Blocking, and the ONC Health IT Certification Program

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National Coordinator for Health Information Technology
Office of the National Coordinator for Health Information Technology
U.S. Department of Health and Human Services
Washington, DC 20201

We strongly support
- Making a patient's electronic health information (EHI) more accessible to the patient
- Clear conditions/requirements for health information technology developers related to protecting data rights, privacy, and security
- Health IT developers defining, developing, and making available Application Programming Interfaces (APIs) for access and exchange of EHI by consumers without special effort

We are particularly supportive of increasing innovation within the healthcare industry by giving patients and patient approved providers improved access to EHI, to enable better decision-making in selecting care and related treatments. We place enormous importance on a patient having access to all of their electronic health information without charge. Particularly, we are pleased to see that the ONC proposes to promote policies that ensure a patient's electronic health information is accessible to that patient and their designees in a way that can be communicated and shared with the patient's healthcare providers, researchers, and adheres to all withstanding privacy and consent criteria.

- We recommend a very broad definition of health care provider, including, but not limited to, nurses, OT, PT, and Speech Pathologists, to allow them all the same incentives and also requiring that no health care provider purposefully limit patient information from being shared with other individuals or entities approved by the patient.

- We would like to see that clear and specific information be provided for patients about accessing a patient portal, and that patients have easy access to any needed technical assistance to utilize portals.
- While standards are critical and essential, we also support allowing unstructured data, perhaps in a template form, to be made useful to patients, clinicians, and researchers sooner than later. This would also allow access to information in a way that doesn't entirely depend on the health IT company's approval or actions.
- With regard to registries, we support efforts to improve the flow of clinical information from EHR systems to data registries, including disease specific registries. We would like to see these registries more interoperable, cross-condition, structured, and useful to individuals, as well as clinicians and researchers. We applaud the inclusion of disease specific registries, especially ones initiated and managed by people with a lived experience of disease. Some of us have run such registries for 25 years, and we are glad to see they are now considered on par with other more traditional registries. We are particularly glad to see APIs will also be required of these registries to transmit information to patients. Technology has advanced quickly in this regard, and it is a fundamental principle of many of them to provide information back to their members.

Thank you for the opportunity to comment.

Sincerely,

Sharon F. Terry, MA
President and CEO
Genetic Alliance

Signers:
AliveAndKickn
Barth Syndrome Foundation
Bobby Jones Chiari & Syringomyelia Foundation
Cure HHT
Ehlers-Danlos Society
Fabry Support & Information Group
Fibrolamellar Registry
FND Hope International
Foundation for Prader-Willi Research
G-PACT
Hannah's Hope Fund for GAN
LunaPBC, Inc.
MLD Foundation

National Foundation for Ectodermal Dysplasias
PSC Partners Patient Registry
Rare Army
The ARPKD/CHF Alliance
The Transverse Myelitis Association
Turner Syndrome Society of the United States
United Mitochondrial Disease Foundation