

A Consensus Letter
to the HHS Office of Civil Rights and the Centers for Medicare and Medicaid Services
on the Need to Finalize the Proposed Rule to
Expand the Rights of Patients to Access their Test Results

October 26, 2012

The Honorable Kathleen Sebelius
Secretary
United States Department of Health and Human Services

William V. Corr
Deputy Secretary, Department of Health and Human Services

Leon Rodriguez
Director, Office of Civil Rights

Marilyn Tavenner
Administrator, Centers for Medicare and Medicaid Services

Thomas R. Frieden
Director, Centers for Disease Control and Prevention

cc: Todd Park, United States Chief Technology Officer
Farzad Mostashari, National Coordinator for Health Information Technology
Joy Pritts, Chief Privacy Officer, Office of the National Coordinator for Health
Information Technology
Bryan Sivak, Chief Technology Officer, Department of Health and Human Services

*Re: Support for the 2011 Proposed Rulemaking on the CLIA Program and HIPAA Privacy
Rule; Patients' Access to Test Reports, RIN 0938-AQ38*

Dear Secretary Sebelius, Director Rodriguez, Administrator Tavenner, and Director Frieden:

On September 14, 2011, your agencies put forward a proposed rulemaking, RIN 0938-AQ38, which would expand patients' right to access their health records by giving them the right to receive their test results directly from laboratories. **We are writing to voice our whole-hearted support for that proposed rule** and to encourage you to do all in your power to finalize it promptly, so that the current obstacles patients face in gaining access to their test results are removed as soon as possible.

Background. The 2003 HIPAA Privacy Rule gave individuals the crucial right to access their protected health information. The 2009 HITECH Act modernized and broadened patient access rights further by allowing individuals to obtain copies of their records in electronic format. **Unfortunately, however, these access rights have proved illusory when it comes to laboratory test results.** The reason is that the Privacy Rule created an exception¹ from access

¹ 45 CFR § 164.524(a)(iii)(A) (2011).

rights for protected health information maintained by a covered entity subject to the Clinical Laboratory Improvements Amendments of 1988 (CLIA). In addition, regulations issued by the Centers for Medicare and Medicaid Services (CMS) permit test results to be released only to authorized persons and the individual responsible for using the test results. “Authorized persons” is defined as “an individual authorized *under State law* to order tests or receive tests, or both [*emphasis added*].”²

Because only a few states expressly authorize labs to release test results directly to patients, this regulatory framework prevents patients in all but a few states from having direct access to copies of their test results. The combination of the HIPAA Privacy Rule, the CMS CLIA rule, and state laws thus puts test results in a uniquely restricted category compared to other health information, which greatly impairs patients’ ability to see, save, use, and share their own test results.

The Department’s Proposed Rule. Your proposed Rule would break through this regulatory barricade and grant individuals the right to receive their test results directly from laboratories in all 50 states. The proposed Rule would accomplish this by (a) specifying that, upon patient request, laboratories may provide access to completed test results that, using the lab’s authentication process, can be identified as belonging to that patient,³ and (b) removing the exceptions for CLIA-certified and CLIA-exempt labs from the HIPAA right of access to one’s protected health information.⁴

Your proposed Rule explained that, according to the Health Information Technology Policy Committee, many stakeholders, including some laboratories, public health authorities, electronic health record vendors, health policy experts, health information exchanges, and providers, perceive that these CLIA barriers impede patient access to their records and prevent patients from taking a more active role in their personal health care decisions. You also explained that providing direct patient access to lab results would support our national commitments and goals regarding the widespread adoption of EHRs, robust health information exchange, and greater patient engagement in healthcare.

Our position. We fully support the proposed Rule. Our reasons include:

- First and foremost, granting patients direct and timely access to test results will improve clinical care and patient outcomes. Patients can respond faster and more appropriately when they learn their test results quickly. For example, it is not unusual that the appropriate response to a particular lab result is to make an appointment with a relevant specialist or take other actions. But difficulties in reaching the ordering doctor may unnecessarily delay appropriate next steps, as well as create unnecessary stress during the “phone tag” period.
- Even worse, some patients are being harmed by *never* learning of their lab results. Approximately 7% of clinically significant test results – tests that would have a potential impact on clinical care – are *never* reported to patients, potentially delaying

² 42 CFR § 493.2 (2011).

³ 42 CFR § 493.1291 (2011).

⁴ 45 CFR § 164.524 (2011).

or preventing important treatment decisions and causing harm.⁵ Giving patients direct access to their results would help reduce the number of test results lost entirely.

- We do not think that patients' direct receipt of their own lab results will cause them to suffer undue emotional harm, particularly since a provider can communicate promptly to provide context and interpretation. Some health systems have, in fact, found the opposite to be true; Kaiser Permanente has shown that delivering lab results online directly to patients in a timely fashion improves provider/patient relationships.⁶ In fact, even the availability of clinical notes written by one's physician has been recently shown to have minimal negative effects and significant positive outcomes. The results from three different health systems showed that patients accessed notes frequently, a large majority reported clinically relevant benefits and minimal concerns, and doctors reported a negligible increase in workload. No doctors elected to stop sharing their notes with patients and 99% of patients wanted the practice to continue.⁷
- A common reason for requesting one's lab results is often, somewhat ironically, so that they can be handed directly to a specialist or a new provider, especially when the circumstances are urgent. *Patients can only deliver what they possess.* If patients routinely access and save their lab results, they'll be available quickly in emergencies. As stated recently by Lygeia Ricciardi, acting director of the Office of the National Coordinator's Office of Consumer eHealth, "We want people to think about being empowered with information before that crisis hits."⁸
- The clinical consequences of timely, direct access to one's health information are significant. Todd Park, the federal Chief Technology Officer, recently explained, "When patients have timely access to their records, they can spot errors and omissions, which improves treatment outcomes and helps them avoid unnecessary procedures. Getting access to your own data isn't an abstract thing. It can literally make the difference between life and death."⁹
- The proposed Rule would help save money for our overburdened health care system. When patients cannot easily obtain and save copies of lab results and procedures, and thus cannot quickly share them with other providers, expensive tests and procedures often must be unnecessarily repeated.

⁵ Casalino LP, Dunham D, Chin MH, et al. Frequency of Failure to Inform Patients of Clinically Significant Outpatient Test Results. *Arch Intern Med.* 2009;169(12):1123-1129.

⁶ Silvestre, A, Sue, V, and Allen, J, *Electronic Health Records: If You Build It, Will They Come? The Kaiser Permanente Model Of Online Health Care*, Health Affairs, March/April 2009 28:2334-344; doi:10.1377/hlthaff.2

⁷ Delbanco, Tom MD, *Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead*, Annals of Internal Medicine, Oct. 2, 2012, <http://annals.org/article.aspx?articleid=1363511>.

⁸ Sarasohn-Kahn, Jane, *Health IT Promotion Goes Direct-to-Consumer*, iHealthBeat, Sept. 11, 2012, <http://www.ihealthbeat.org/perspectives/2012/health-it-promotion-goes-directtoconsumer.aspx>.

⁹ Burns, Ed, *ONC looks to make Blue Button public, boost patient engagement*, SearchHealthIT.com, Sept. 12, 2012, <http://searchhealthit.techtarget.com/news/2240163116/ONC-looks-to-make-Blue-Button-public-boost-patient-engagement>

- Currently, an exciting development we are seeing in the technology space today is the plethora of consumer-engaging, patient-empowering apps that provide actionable information consumers can use to improve their health. Much of this tech activity has been spurred by our national investment in HIT and EHRs. However, the success of many of these creative solutions hinges on patients having meaningful, practical access to their health data. Keeping crucial lab results excluded from the information patients can access not only hurts them directly, but also will hurt them indirectly by impeding the development of useful tools that could enable them to manage their health more effectively.
- Finally, as your proposed Rule pointed out, allowing direct access to lab results is entirely consistent with our national emphasis on the importance of patients being more engaged in managing their health. This priority, which has been consistently pursued through HITECH, Meaningful Use incentives, Medicare improvements, veterans' health programs, and other national initiatives, is crucial. Your proposed Rule would fill a gaping hole in patients' ability to access, appropriately respond to, save, and share their health information.

Thank you for issuing this proposed Rule and for considering our comments. We urge you to finalize it quickly. Further delays will not only continue to frustrate and harm patients but also are inimical to our national commitment to patient engagement and a more efficient and effective health system.

The list of the 637 individuals and organizations signing this consensus letter is attached.

**The Undersigned Support the Consensus Letter In Favor of Finalizing
The Proposed HHS Rule
Allowing Direct Patient Access to Lab Test Results**

	First Name	Last Name (and professional credentials, if applicable)	Position (Optional)	Organization/Affiliation (Optional)
1.	Andrea	Ability	Board Member, Ovarian Cancer Survivor	Caring Together
2.	Carter	Adamson	Co-Founder	Rdio
3.	Brian	Ahier	President	Gorge Health Connect, Inc
4.	Carolyn	Aldigé	President, Founder	Prevent Cancer Foundation
5.	Marc	Alexander	CEO and Co-Founder and Postdoc	PROVITAL, Inc. and Stanford Genetics
6.	Nancy	Amato	Community Manager	Social Code
7.	Michael	Amie	Student	Portland State University
8.	Margaret	Anderson	RN manager	Nathan Littauer
9.	Bonnie	Anderson	CEO, Co-Founder	Veracyte, Inc.
10.	Misha	Angrist (PhD)	Assistant Professor of the Practice	Duke University Institute for Genome Sciences & Policy
11.	Diana	Autin	Executive Co-Director	Statewide Patient Advocacy Network of NJ, Family Voices NJ
12.	Michael	Avery	Support Analyst	PDS Tech, Inc.
13.	Linda	Avey	CEO	Curious, Inc.
14.	Florence	Bailes	Speaker Manager	O'Reilly Media
15.	Ileana	Balcu	Communications Lead	Society for Participatory Medicine
16.	Karen	Ball	President, CEO	Sturge-Weber Foundation
17.	Ayeh	Bandeh-Ahmadi	Ph.D. Candidate	University of Maryland
18.	Jessica	Barker	Director of Government Affairs	The Mesothelioma Applied Research Foundation
19.	Daniel C.	Barth-Jones (MPH, PhD)	Assistant Professor of Clinical Epidemiology Department of Epidemiology	Mailman School of Public Health Columbia University
20.	Jim	Beall	President	Beall F. P.
21.	Christine	Bechtel (MA)	Vice President	National Partnership for Women & Families
22.	Patricia	Beggiato	Fundraising & Advocacy	The Mastocytosis Society
23.	Tyler	Bell	Director of Product	Factual
24.	Carla	Berg	Forum Founder	ParticipatoryMedicine.org (@s4pm)
25.	Michael	Bernstein	Founder	Urbsly
26.	Mate	Bestek	Owner	Activis
27.	Greg	Biggers	CEO	Genomera
28.	Amanda	Bishop	Founder	Stop ChartChasing
29.	Gina	Blaber	VP Conferences	O'Reilly Media, Inc.

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30.	Christine	Blouch	Professor	ICD User Group
31.	Drina	Boban		WellnessFX
32.	Jason	Bobe	Executive Director	PersonalGenomes.org
33.	Thomas	Bognanno	President, CEO	Community Health Charities of America
34.	Richard	Bookman	Faculty	University of Miami
35.	William R. ("Bill")	Braithwaite (MD, PhD, FACMI, FHL7)	Consultant	Health Information Privacy and Strategy
36.	Jeff	Brandt	Mobile Health Consultant	
37.	Kathy	Brill (Med, MPS)	Executive Director	Parent to Parent USA
38.	Juliana	Brixey	Assistant Professor	UTHealth University of Texas Health Science Center at Houston
39.	Andrew	Broman		Morgridge Institute for Research
40.	Apryl	Brown		Detroit Medical Reserve Corps
41.	Christine	Brown	Executive Director	National PKU Alliance
42.	Ted	Brown (MD, PhD, FACMG)	Director	Institute for Basic Research in Developmental Disabilities
43.	Clyde	Bryant		Pierpont Syndrome
44.	Kathleen	Buckley	President	Team Sanfilippo Foundation
45.	Wylie	Burke (MD, PhD)	Professor Chair	Department of Bioethics and Humanities University of Washington
46.	Hayman	Buwan	Resident Physician	McMaster University
47.	Hugo	Campos	Cardiac Patient, Patient Advocate	ICD User Group
48.	Kenneth	Carter	Co-Founder, Chairman	Noble Life Science, Inc.
49.	Joleen	Chambers	Patient Advocate	FiDA Failed Implant Device Alliance
50.	Steven	Chapkin	Vice President, Sales & Business Development	Dossia Service Corporation
51.	Robert	Chase (JD)		Law Offices of Robert S. Chase
52.	Grace	Chen	Member	Caring Together
53.	Thomas	Cheng	Board Member	Cooley's Anemia Foundation
54.	Panha	Chheng	CEO	Personiform
55.	Aneesh	Chopra (MPP)	Senior Advisor	The Advisory Board Company
56.	Joe	Christensen	President	Blaze Streaming Media, LLC.
57.	George	Church (PhD)	Professor Founder President	Harvard Medical School Personal Genome Project PersonalGenomes.org
58.	Priscilla	Ciccariello	Co-President	Coalition of Heritable Disorders of Connective Tissues
59.	Gina	Cioffi	National Executive Director	Cooley's Anemia Foundation

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61.	Kathleen	Clark	Attorney, Founder, Author	Servant Lawyiership
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63.	Hugh	Cline	Professor	Teachers College, Columbia University
64.	Amy	Clugston	Founder, President	Syndromes Without a Name USA
65.	Eli	Cochran	Project Manager	University of California, Berkeley
66.	Matthew	Cockerill	Managing Director	BioMed Central
67.	Monica	Coenraads	Executive Director	Rett Syndrome Research Trust
68.	Amy	Colberg	Director of Governmental Affairs	Brain Injury Association of America
69.	Christy	Collins	President	M-CM Network
70.	Brenda	Conger		Cardio-Facio Cutaneous International
71.	Rhonda	Connolly	President	Children's PKU Network
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77.	Mike	Critelli	President and CEO	Dossia Service Corporation
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79.	Donna	Cryer (JD)	President, CEO	American Liver Foundation
80.	Jonathan	Darer (MD)	Chief Innovation Officer	Geisinger Health System
81.	Frank	Davis	President	Spastic Paraplegia Foundation
82.	e-Patient Dave	deBronkart	Co-Founder, Board Member, Past Co-Chair	Society for Participatory Medicine
83.	Anne	Degheest	Managing director	Medstars
84.	Mary- Angela	DeGrazia-DiTucci	President, Patient Founder	Association of Gastrointestinal Motility Disorders, Inc.
85.	Nathan	DiNiro	Program Manager	SW Houston ACO
86.	Alexandra	Drane	Co-founder, Chief Visionary Officer	Eliza
87.	Billie	Duncan-Smith		CADASIL Together We Have Hope
88.	Karen	Durant (RN, BSN)	President	The NOMID Alliance
89.	Esther	Dyson	Principal	EDventure Holdings
90.	Diane	Edquist Dorman	Vice President of Public Policy	National Organization for Rare Disorders
91.	Naras	Eechambadi	Senior Vice President and General Manager	CSG International

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94.	Gail	Embt	CEO	Kinergy Health
95.	Dwight	Epps	Director	Katsujinken Foundation
96.	Bettina	Experton	President	Humetrix
97.	Roseanne	Fallin	Web producer	O'Reilly Media
98.	Andrew	Faucett (MS)	Director of Policy & Education, Genomic Medicine Institute	Geisinger Health System
99.	Laurie	Fenton	President, CEO	Lung Cancer Alliance
100.	Heather	Ferguson	Executive Director	Lymphedema Advocacy Group
101.	J Tod	Fetherling	Chairman	Stratasan
102.	Muriel	Finkel		Amyloidosis Support Groups, Inc.
103.	Hagen	Finley	Sales Engineer	EMC
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105.	Ann	Fonfa	President	Annie Appleseed Project
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109.	Tamara	Frazier	Attorney	Fish and Robertson
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116.	Bruce	Gaughran	President	The Kennedy's Disease Association
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127.	Bastian	Greshake	Co-Founder	openSNP
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129.	Adrian	Gropper (MD)	Principal	HealthURL
130.	Avram	Grossman	President/CEO	E-Novative, Inc.
131.	William	Gunn	Head of Academic Outreach	Mendeley
132.	Helge	Gunther	Retired business owner	Cytran
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135.	Julia	Hallisy	Founder and President	The Empowered Patient Coalition
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138.	David	Harlow (JD, MPH)	Principal	The Harlow Group LLC
139.	Mark	Harmel	MPH Student	USC
140.	Helen	Haskell	President	Mothers Against Medical Error
141.	Don	Haut	Vice President	The Medroves Co.
142.	Joseph	Healy	Founder & CEO	Health Team LLC
143.	Diane	Heditsian	Chief Executive Officer, Creative Officer	deClarity bioCommunications
144.	Chris	Hempel	Founder	Addi and Cassi Fund
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148.	Jamie	Heywood	Co-Founder, Chairman, Founder, Former CEO	Patients Like Me ALS Therapy Development Institute

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152.	Kim	Hollander	Executive Director	Oxalosis & Hyperoxaluria Foundation
153.	Pablos	Holman	Hacker	Intellectual Ventures Lab
154.	Kent	Horvath	Medical Student	New Jersey Medical School
155.	Gilberte	Houbart	Director, Media and Product Design	Delta Capital Partners
156.	Erich	Huang	Director, Cancer Research	Sage Bionetworks
157.	Graham	Hughes	Chief Medical Officer	SAS Institute
158.	Karina	Hughes		Genentech
159.	Kevin	Hughes (MD, FACS)	Surgical Director	Breast Cancer Screening, Massachusetts General Hospital
160.	Jason	Jacobs	Co-Founder, CEO	FitnessKeeper
161.	Leila	Jamal	Genetic Counselor	Kennedy Krieger Institute
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165.	Vicki	Kalabokes	CEO	National Alopecia Areata Foundation
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167.	Peter	Kapitein	President	Inspire2Live
168.	George	Kassabgi	Co-Founder	Keas.com
169.	Jeffrey	Kaufman	Executive Director	Adenoid Cystic Carcinoma Research Foundation
170.	James	Kean	CEO	WellnessFX
171.	Chris	Keene	Vice President	VMware
172.	Donald	Kemper	Founder, CEO	Healthwise
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185.	Jessica	Ladd	Executive Director	Sexual Health Innovations
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193.	Rigby	Leighton		R Leighton, LLC
194.	Susan	Levin	President	Lung Cancer Circle of Hope
195.	Howard	Liebers (MPH)	Founder, CEO	MarbleRoad
196.	David	Lindeman (PhD)	Director	Center for Technology and Aging
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198.	Michele	Lloyd-Puryear (MD, PhD)	Special Advisor	National Institutes of Health
199.	Susan	Lomas	President	Phelan-McDermid Syndrome Foundation
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201.	Martha	Lopez-Anderson	Chair, Board of Directors	Parent Heart Watch
202.	Rob	Lord	Founder & CEO	Pioneers of the Imminently Feasible
203.	Susan	Love (MD)	President	Dr. Susan Love Research Foundation
204.	Yasmin	Lucero	Statistician	Signal to Noise Consulting
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206.	Desiree	Lyon	Executive Director	American Porphyria Foundation
207.	Scott	Mace	Senior Technology Editor	HealthLeaders Media
208.	Roger	Magoulas	Research Director	O'Reilly Media
209.	Erin	Maneri	Manager	Accenture Technology Labs
210.	Lisa	Mann	Copywriter	O'Reilly Media, Inc.
211.	Michael	Maranda	Founder, CEO	Open Stewardship Group
212.	David	Margulies (MD)	Executive Director	Gene Partnership, Boston Children's Hospital
213.	Kendra	Markle	Researcher	Stanford University

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215.	Philip	Marshall (MD, PhD)	Healthcare Technologist	Consumer Advocate
216.	Ellen	Marshall (MS, L-CSW)	Director of Oncology Support Programs	Benedictine Hospital
217.	Robin	Maupin		OASIS of Southern California
218.	Carol	McCall	Chief Strategy Officer	GNS Healthcare
219.	Vicki	McCarrell	President	The Moebius Syndrome Foundation
220.	Kathryn	McCurdy	Owner	Katie McCurdy Experience Design
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222.	Steve	McPhail	President, CEO	Expression Analysis, Inc.
223.	Graham	Melcher	VP Engineering	WellnessFX
224.	Romain	Mervil	Manager	Fabernovel
225.	Michael	Millenson	President-Elect	Society for Participatory Medicine
226.	Gary	Miller		AAUG
227.	Darryl	Mitteldoft (LCSW)	Director	The LGBT Cancer Project
228.	Staci	Molyneaux	System Analyst	UHS Hospitals
229.	Kathleen	Mott (RN, MS, NP, APNG)		North Bay Cancer Risk Assessment Services
230.	John	Mountz (MD, PhD)	J.W. Goodwin Professor of Medicine	Dept. of Medicine, Division of Rheumatology, University of Alabama
231.	Steve	Munini	COO	Dossia Service Corporation
232.	Bernard	Munos	Founder	InnoThink Center for Research in Biomedical Innovation
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234.	Beth	Najberg	Principal	Beginnings
235.	Sharon	Natale		Cholangiocarcinoma.org
236.	Andrew	Natenshon	Head China Research Strategy and Operations	Novartis Vaccines
237.	Steven	Nelson	Co-Founder	BigEvidence (medical evidence for clinicians)
238.	IPH	NET	CEO	IPH-NET
239.	Scott	Nicholson	Chief Data Scientist	Accretive Health
240.	Sean	Nolan	Distinguished Engineer	Microsoft HealthVault
241.	Don	Norsbeck (Esq.)	Chief Architect	Virtual Computing Company

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243.	Miriam	O'Day		Alpha-1 Foundation, Alpha-1 Association, COPD Foundation
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245.	Tim	O'Reilly	CEO	O'Reilly Media, Inc.
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249.	Jay	Parkinson	CEO	Sherpaa
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251.	Lynn	Pedraza (PhD)	Executive Director	Family Voices
252.	Mary	Pendergast (JD, LLM)		Pendergast Consulting
253.	Sara	Peyton	PR Manager	O'Reilly Media
254.	Brad	Phillips		Fabricatorz
255.	Jon	Phillips	Founder	Fabricatorz
256.	Sharon	Pierce	Strategic Accounts Manager	O'Reilly Media
257.	Jeanne	Pinder	CEO, founder	ClearHealthCosts
258.	Brigitte	Piniewski	CMS	PeaceHealth Laboratories
259.	Matthew	Pohlman	Data Scientist, Analytics Lead	Explorys
260.	Daniel	Pucci	VP	Allscripts
261.	Ernesto	Ramirez	Community organizer	Quantified Self Labs
262.	Taran	Rampersad	Managing Partner	KnowProSE LLC
263.	William	Raynovich	Associate Professor	Creighton University
264.	Heidi	Rehm (PhD, FACMG)	Director	Laboratory for Molecular Medicine, Partners Healthcare Center for Personalized Genetic Medicine
265.	Jacqueline	Reinhard	Executive Director	SHARE: Self-help for Women with Breast or Ovarian Cancer
266.	Tiffany	Renee	Vice Mayor	City of Petaluma
267.	Sherry	Reynolds	Executive Director	Alliance4Health
268.	Catherine	Rice	Executive Director	International Essential Tremor Foundation
269.	Rebecca	Richman	Operations Analyst	O'Reilly Media
270.	Michelle	Rintamaki	President, Director	Kids With Heart National Association for Children's Heart Disorders, Inc.

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271.	Peter	Robinson (MD)	Professor of Medical Genomics	Institute for Medicinal Genetics and Human Genomics, Berlin, Germany
272.	Dan	Rode (MBA,CHPS, FHFMA)	Vice President, Advocacy and Policy	AHIMA (American Health Information Management Association)
273.	David	Rogers		Excira Technologies
274.	Kari	Rosbeck		Tuberous Sclerosis Alliance
275.	Clarke	Ross	Policy Associate	American Association on Health and Disability
276.	Laura	Ruma	Director	O'Reilly Media
277.	Wojciech	Rychlik (PhD)		Molecular Biology Insights, Inc.
278.	Marijo	Rymer	Executive Director	The Arc of Colorado
279.	Soheil	Saadat (MD)	CEO & Founder	GenieMD, LLC
280.	Paul	Saarinen	CEO	Miinome, Inc.
281.	Lisa	Salberg		Hypertrophic Cardiomyopathy Association
282.	Lori	Sames	Executive Director	Hannah's Hope Fund
283.	Daniel Z.	Sands (MD, MPH, FACP)	Assistant Clinical Professor of Medicine, Co-Founder, Past President	Harvard Medical School, Society for Participatory Medicine
284.	June	Sargent	Marketing Consultant	Marketing Moxie
285.	Mark	Schiller, MD	Co-Founder	Doctor Patient Medical Assn
286.	Neil	Schmidt	Principal Analyst	ARM Resource Systems
287.	Jody	Schoger	Founder	WomenWithCancer
288.	Lisa	Schoyer (MFA)	Founder, Chair	RASopathies Network USA
289.	Conrad	Schuerch (MD)	Medical Director of Lab Services, Chair- Lab Medicine	Geisinger Health System
290.	Michael	Scott	Chairman, Board of Directors	National Organization for Rare Disorders
291.	Cindy	Scurlock	Executive Director	Turner Syndrome Society of the United States
292.	Kathryn A.	Serkes	CEO & Chairman	Doctor Patient Medical Assn
293.	Hemant	Shah	Sr. Biomedical Informatics Researcher	Henry Ford Health System
294.	Laura	Shawver (PhD)	Founder	The Clarity Foundation
295.	Susan	Shea	Behavior Analyst	Behavioral Network, Inc
296.	Robert	Shelton	CEO Former Executive Chairman	Private Access, Inc. Klinefelter Syndrome & Associates
297.	Steven	Sikes	Founder/President	QUESTCOURSE, LLC
298.	Morgan	Simonnet		WellnessFX

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299.	Warren	Smith	Managing Director	Forest Island
300.	Tor	Solli-Nowlan	President	LA Biohackers
301.	Andrew	Spiegel (Esquire)	CEO	Colon Cancer Alliance
302.	Dean	Sproles	CEO	Iverson Genetic Diagnostics, Inc.
303.	Theresa	Strong (PhD)	Strong (PhD)	Foundation for Prader-Willi Research
304.	Robin	Strongin	President, CEO	Amplify Public Affairs
305.	Peter	Suber	Director	Harvard Open Access Project
306.	Sara	Sukalich (MD)	Chair, Board of Directors	Angioma Alliance
307.	Destry	Sulkes	Co-founder	Medivo, Inc
308.	Ilene	Sussman	Executive Director	VHL Family Alliance
309.	Katherine	Sutherland (MD)		Women Physicians GYN Medical Group, Inc.
310.	Keith	Swafford	Sales Associate	O'Reilly Media
311.	Naz	Sykes	Executive Director	Dr. Susan Love Research Foundation
312.	Richard Gordon	Syne (DMin)	President, CEO	CurePSP
313.	Patty	Taormino	Board of Directors	Team Sanfilippo Foundation
314.	David	Tegay (DO, FACMG, FACOI)	Chair Dept. of Medicine	New York Institute of Technology New York College of Osteopathic Medicine
315.	Cara	Tenenbaum	VP for Policy	Ovarian Cancer National Alliance
316.	Sharon	Terry	President, CEO	Genetic Alliance
317.	Makani	Themba	Executive Director	The Praxis Project
318.	Mary Lou	Thompson	President, CEO	Benign Essential Blepharospasm Research Foundation
319.	Jennifer	Thornburn	Online Communities Officer	AKU Society
320.	Susan	Thornton	CEO	Cutaneous Lymphoma Foundation
321.	Mark	Thornton (MD, MPH, PhD)	President	Sarcoma Foundation of America
322.	Docktur	Todd	CEO/President/Senior Executive Consultant	The Consultants Group
323.	Jeffery	Toughill	President	Histocytosis Association
324.	Keith	Toussaint	Director of Collaborative Development	Mayo Clinic
325.	Matthew	Trentacoste	Owner	Empty Research
326.	Mary	Treseler	Editorial Strategist	O'Reilly Media Inc.
327.	Kari	Ulrich	e-patient	FMD Chat
328.	Jen	van der Meer	Adviser	Luminary Labs
329.	Mascha	Van Dort	Patient Advocate	Inspire2Live

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330.	Brian	Van Ness	Director	Medical Genomics, University of Minnesota
331.	Chip	Vanek	CTO	JumpDaily
332.	Timothy	Vaughan	Research Scientist	Patients Like Me
333.	Marianne	Vennitti	Administrator	Alliance for FCryoglobulinemia
334.	Jacque	Waggoner	CEO	Hunter's Hope Foundation
335.	Jonathan	Wald	Director, Patient-Centered Technologies	RTI International
336.	Ann	Waldo (JD)	Partner	Wittie, Letsche & Waldo, LLP
337.	Betsy	Waliszewski	Sr. Marketing Manager	O'Reilly Media
338.	Jaimey	Walking Bear	Marketing Manager	O'Reilly Media
339.	Stephen	Walli	Technical Director	Outercurve Foundation
340.	Will	Ware	Software Engineer	GenomeQuest, Inc.
341.	Kalina	Warren	President	National Adrenal Diseases Foundation
342.	Fredrick	Watters	ER Nurse/FNP Student	EMMC/UMaine
343.	Jennifer	Webb	Freelance writer/editor	O'Reilly Media, Blue Pencil Co.
344.	Larry	Weiss	CSO	CleanWell Company
345.	Gregory	Weiss		APBD Research Foundation
346.	Ben	West	Patient	Insaulaudit Author
347.	Earle	West	CTO	Transactional Web LLC
348.	Cheryl	West	Director of Governmental Affairs	American Association for Respiratory Care
349.	Robert	West, Jr.	Associate Professor	SUNY Upstate Medical University
350.	Kathie	Westpheling (MPH)	Executive Director	Association of Clinicians for the Underserved
351.	Cherie	Whitaker	Publicist	CLW Public Relations
352.	Lale	White	Executive Chairman, CEO	XIFIN
353.	Wendy	White	Board Member	National Organization for Rare Disorders
354.	Jeanne	Whiting		Desmoid Tumor Research Foundation
355.	John	Wilbanks	chief commons officer	Sage Bionetworks
356.	John	Wilbanks	Senior Fellow, Chief Commons Officer	Kauffman Foundation, Sage Bionetworks
357.	Deborah	Williams-Muhammad	Advocate	Community Economic Development
358.	Bart	Windrum	End of Life reform advocate author/speaker	Axiom Action
359.	Sara	WInge	VP	O'Reilly Media
360.	Johann	Winkler	Chief Scientific Officer	GNS Healthcare

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361.	Kay	Wissman	Former Director of Governmental Relations	Y-ME National Breast Cancer Organization, Women With Hope
362.	Steve	Wojcik	VP of Public Policy	National Business Group on Health
363.	Jill	Wood	CFO, Co-Founder	Jonah's Just Begun
364.	Susan	Woods	MD	Society for Participatory Medicine
365.	Dean	Wray	Senior Market Analyst	Seeker Solutions
366.	Bill	Wright	Treasurer	LinuxFest Northwest
367.	Jeff	Wuchich	President	Alternating Hemiplegia of Childhood Foundation
368.	William A.	Yasnoff (MD, PhD)	Chairman, CEO	Health Record Banking Alliance
369.	Spencer	Young		Fabricatorz
370.	Colleen	Zak		ARPKD/CHF Alliance
371.	Karolina	Zatz		WellnessFX
372.	Steven	Zecola	Managing Director	Competitive Strategies, LLC
373.	Roni	Zeiger (MD)	CEO	Smart Patients, Inc.
374.	Peggy	Zuckerman	Patient, Chief Investigator	Invoke Health
375 to 637	<p>All of the above signatories listed their position and organizations. In addition, 263 individuals, whose names we are not posting publicly, signed in their individual capacity.</p> <p>The total number of signatories to this letter is 637.</p>			