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Stories

The power of parent scientists

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Parent scientists lead a journey to bring surveillance severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) testing to public schools across the state of Massachusetts and beyond.

It's hard to believe that we actually did it.

I want to tell you a story. A story about what is possible at the interface of modern science and public education. This is a story of scientific volunteerism, a story of consensus building in the arena of public policy, and a story of fighting to put public-school teachers and kids first. But it's also a story about coronavirus disease 2019 (COVID-19)—a disorienting crisis that unmoored a group of us from our normal expectations, allowing us to achieve something that we might never have thought possible.

Although I and a hundred of my colleagues in Massachusetts are the protagonists in this narrative, it's really not a story about us. If you are a scientist and have a child in the public schools, this is a story about you. It's about what parent scientists everywhere are capable of—or could be capable of—when we establish meaningful partnerships with educators and administrators to solve urgent challenges at the intersection of education and science.

And what could have felt more urgent this year than bringing kids and teachers back to school safely?

I'd like to tell you about the unexpected journey a group of parent scientists took to create a data-driven framework to help achieve this critical goal. Building a grassroots organization over nights and weekends. Establishing a generalizable framework for routine severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) surveillance testing in public schools. Testing tens of thousands of students and teachers every week. Catching asymptomatic cases. Preventing outbreaks by catching cases in real time, thereby reducing fear among teachers and families. And striving to do so equitably across every district in Massachusetts.

“We needed to try to replace fear with data.”

Above image: The COVID-19 pandemic exposes gaps and opportunity at the intersection of public schools and rapidly evolving science.



The scientist-educator paradox

At face value, it seems unlikely that I would become one of the leading voices calling for SARS-CoV-2 surveillance testing in public schools throughout the state of Massachusetts. After all, my professional expertise is in cancer biology. My laboratory is focused on functional genomics approaches for deciphering cancer targets.

However, my firm conviction has always been that my role—and the role of scientists more generally—is to serve society. Perhaps like you, I got into science in the first place to make a difference, to change the world in some fundamental way—by charging into the unknown, working collaboratively, sharing information, and helping to make really hard things, even things that seemed “impossible,” not only possible but straightforward. And not just by publishing an exciting *Cell* paper, but by using science to actually change the lives of members of our communities for the better.

Imagine looking back at the end of your career and realizing that you had done *that*?

So, it follows naturally that I've always found a passion at the intersection of science, communication, and education. My wife, Julie, is a gifted science educator who shares this passion. She teaches AP Biology and a biotechnology and personal genetics elective course in the public high school in our community. Seeing the untapped potential of local scientific expertise, she has worked to make it available to teachers, enabling them to teach cutting-edge science to kids. She has built a career working to close this recalcitrant gap between scientists and educators.

“Our first Zoom call had 6 people. By the 12th, we had nearly 100.”

It's paradoxical that this gap is so hard to close. After all, amazing scientists and medical professionals live in every state. Many of them are parents of kids right there in the public schools, hungry to support educators as community volunteers. Others are amazing scientific educators, hungry to engage scientists. They're part of the same circles. They are right there.

A high-quality matchmaking function between parent scientists and educators is missing in America. Before the COVID-19 pandemic, that disconnect was visible mainly within discussions involving science curriculum improvement. In 2020, the stakes changed.

A walk on the beach

By early in the summer of 2020, principals and superintendents across the country were scrambling to make sense of the rapidly changing science. What did we know about the virus? What mitigation strategies would really work? How would we ensure a safe return to school in the fall?

Fear and uncertainty—especially among teachers like my wife—were running rampant. The magnitude of the challenge was immense. For instance, a quick calculation revealed that every school day roughly 1 out of 90 children and staff would likely present with symptoms (cough, sore throat, etc.) that overlapped with those of COVID-19. How would we know whether these individuals had the disease or something far more benign? And, most critically, could we find the 50% of positive individuals that were asymptomatic carriers of the virus? Could early detection be an additional mitigation strategy that, together with masking and distancing, could help prevent outbreaks?

It was a walk on the coast of Maine over the July 4 weekend that led Julie and me to a realization that would fundamentally upend the next nine months of our professional lives. We realized that there was only one path forward: we needed to try to replace this fear with data. We needed to find a way to help public school districts test students for viral infection on an ongoing basis. Like all other on-site employees of the Broad Institute of MIT and Harvard, in Cambridge MA, I was being tested two times per week; this allowed us to safely open laboratories with minimal fear of viral spread. But was it possible to do the same in public schools? Could this really be done?

And, most importantly, would it make a difference?

By midsummer, my amazing colleagues at the Broad had converted our sequencing facility into one of the nation's largest COVID-diagnostics centers. The incredible leadership of the entire Broad Genomics Platform team had found a way to process tens of thousands, then hundreds of

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thousands, and then millions of diagnostic tests for organizations everywhere. The results were outstanding. It seemed scientifically possible to measure the impact of SARS-CoV-2 within any organization, in real time. By late summer, other regional laboratories such as Ginkgo Bioworks and Mirimus Labs were also ramping up their COVID-19 diagnostic capacity. Together, these laboratories stood ready to serve any community that could self-organize and marshal funds in time.

But despite the labs' readiness, the urgency from the schools' side seemed missing. Principals, superintendents, school nurses, and local boards of health were grappling with so many things. The complexity of reopening schools was immense.

Could parent scientists help?

Starting local

On July 3, 2020, Julie and I began our journey. We emailed our local superintendent of schools asking if testing was under consideration and asked for support in mapping out a local strategy.

But we knew that sending emails wasn't going to be enough. First, we would need to clearly articulate the scientific strategy and rationale. Next, we would need to develop a plausible financial strategy for resourcing a pilot. Finally, we would need to carefully articulate an operational strategy, breaking down the vast complexity into manageable pieces that could be tackled one by one.

We were not COVID experts, but we knew where to find them: right within our parent community. By July 16, 2020, we had found outstanding parent scientists and parent physician scientists in our community willing to serve. Together with our school district's superintendent and head nurse, we met late in the evening multiple times over the course of a single week.

During the very first discussion in July, our group decided to make equity a core tenet of our work. We decided that the goal of piloting a testing program in one district must be explicitly to develop a general framework for any district in the state or nation to follow. In addition, we wanted to enable every district to use our framework; we didn't want to simply leave that task to others. But first we had to show proof of concept somewhere. Our community in Wellesley, MA was extremely fortunate in that our low COVID rates (related to the socioeconomic and racial demographics of our community) made it possible to even consider reopening. This privileged position provided a key opportunity to pilot a testing concept which could then help others who, because they were bearing the brunt of the pandemic, were unable to go first.

By July 28, 2020, we issued our scientific strategy memo. In it, we recommended that our local board of health and school committee consider launching a pilot viral-testing program as part of a multi-pronged safety strategy. We suggested the program might not just focus on testing symptomatic individuals but also pilot a weekly surveillance infrastructure and attempt to demonstrate proof of concept for a general framework that other districts could follow.

For asymptomatic testing, we recommended (1) testing everyone prior to returning to school ("time zero baseline testing"), (2) weekly testing for staff, and (3) weekly longitudinal surveillance for at least one school building, such as the high school. This strategy would provide real-time estimation of risk and empirically document whether safety protocols were working.

Most importantly, we pledged that we, as parent scientists, would work hand in hand with our school administration counterparts all the way through the school year.

We next mapped financial strategy, convening local parents with relevant expertise in financial services, private fundraising, and educational philanthropy. Over the next few weeks, we worked with parents with business school expertise to fully map an operations strategy. We interviewed vendors; explored legal, consent, and HIPAA-related issues; tapped local volunteer expertise to vet available testing technologies; and considered challenges ranging from staffing, line management, vendor procurement, and space allocation. We finished our financial and operational

“Parent-scientists have tremendous power to productively shape the future of our local communities and public schools.”

strategy memos by August 16, 2020. And we found a fantastic volunteer parent program manager to run the pilot program in partnership with our school committee, district administration, and nursing staff.

Over a three-day weekend from August 30–September 1, we launched the first phase of our “Safer Teachers, Safer Students SARS-CoV-2 Testing Pilot.” We tested 4,600 students and staff as part of our “Time Zero Baseline” testing. Over 90% of staff and students participated. It was extraordinary. We were able to quarantine the few cases we found and opened our school doors knowing that there were essentially zero cases within our walls.

Now, we were well poised for the next challenge. We realized that taking time away from education to test staff and students weekly wasn’t going to work, and we needed a more affordable option. By October 10, we pivoted to a new pooled testing model, one in which students and staff could spit into take-home tubes over the weekend, registering their tubes’ barcodes with a homegrown app that software engineers in our parent community developed. Tubes were sent to a laboratory with the ability to reflex tests down to a diagnostic result in the occurrence of a positive pool.

Six months later, we’ve run tens of thousands of tests in our town. We have caught over 50 cases. We enabled our district’s administration to act like scientists, in a data-driven manner: when an outbreak occurred in one school’s office, they were able to close only the affected school while leaving the rest of the schools in the district open. This local success was remarkable both in terms of its pace and in terms of its impact.

During this same time period, we discovered that other parent scientists in nearby districts had been organizing around similar discussions and goals; some had also been advocating at the district and state level for school-based testing strategies since the summer. We began discovering each other’s efforts. Momentum started building as we began to talk, coalescing around a key opportunity to work together to address our common goals.

However, each of our local efforts turned out to be just the beginning of the story.

From one to many: Fighting for equitable access

Together with the other parent scientists, as well as many other volunteers from across the community, our commitment to equity—to fight for all districts in Massachusetts across the full spectrum of socioeconomic and ethnic diversity—was codified in the first 10 minutes of our group’s first conversation. In September 2020, we began working in parallel to assemble a diverse coalition across the state.

Initially, six diverse districts came together (Revere, Chelsea, Somerville, Wellesley, Watertown, and Brookline). This diversity was critical: each had made different choices about returning to school, had different geographies (urban, suburban), different infection rates/severe disease health outcomes, and diverse socioeconomic, racial, and ethnic community compositions. The superintendents from all of these districts were fully engaged and driven. We quickly realized that this multi-district COVID testing pilot was the first of its kind in the public school setting, both in the state of Massachusetts and in the nation.

We called ourselves the “Safer Teachers, Safer Students (STSS) Testing Collaborative.”

We never met in person. Nevertheless, the online meetings of the Collaborative community were warm, engaging, and interactive. The group grew to include a wide diversity of stakeholders within the six districts: parent scientists, doctors, superintendents, school nurses, members of boards of health, and others. The urgency of the moment pushed everyone toward action. We stayed up after our kids went to bed, after our day jobs were done, discussing, debating, and sharing information late into the night on bi-monthly Zoom calls that sometimes went until nearly 11 p.m.

Our mission was to assess the feasibility and value of viral testing in the public school setting for the Commonwealth of Massachusetts. We believed if this multi-district effort was successful, it would demonstrate how to reduce fear and anxiety about returning to school, help ensure that in-person public school K-12 learning could continue as long as possible, and increase the safety of



Box 1. Principles for the STSS Testing Collaborative

1. We believe access to expedited testing for both symptomatic and asymptomatic individuals should be universal, regardless of income, race, ethnicity, geography, or social status.
2. We believe that decision-making on the transition states between schooling models should be driven by data on cases and transmission events.
3. We believe that testing in the public school setting should be made available at cost, with no profit motive.
4. We believe that the best technologies and approaches for testing should be available to public schools earlier than, or at the same time as, for-profit corporations.
5. We believe that our educators deserve access to high-quality testing programs equivalent to those available to for-profit corporations.
6. We believe that the development of a general framework of best practices for how public-school SARS-CoV-2 testing adds the most value is urgent and is a matter of social justice.

both teachers and students. Critically, it would ensure that the framework could be generalizable to enable any district in the Commonwealth to follow.

We set a unifying and cohesive culture for our group, establishing mission-based principles guiding our work; see [Box 1](#).

These principles began to attract engagement and attention from others. First, testing vendors that shared these principles joined in the discussion and began exploring ways to work together to support schools. They shared information and ideas and pushed each other to lower costs. Second, economists joined in, bringing new perspectives, connections, and ideas. And third, local, state, and national politicians and policy makers engaged. The strength, vision, and diversity of our group provided a strong platform.

The momentum grew rapidly.

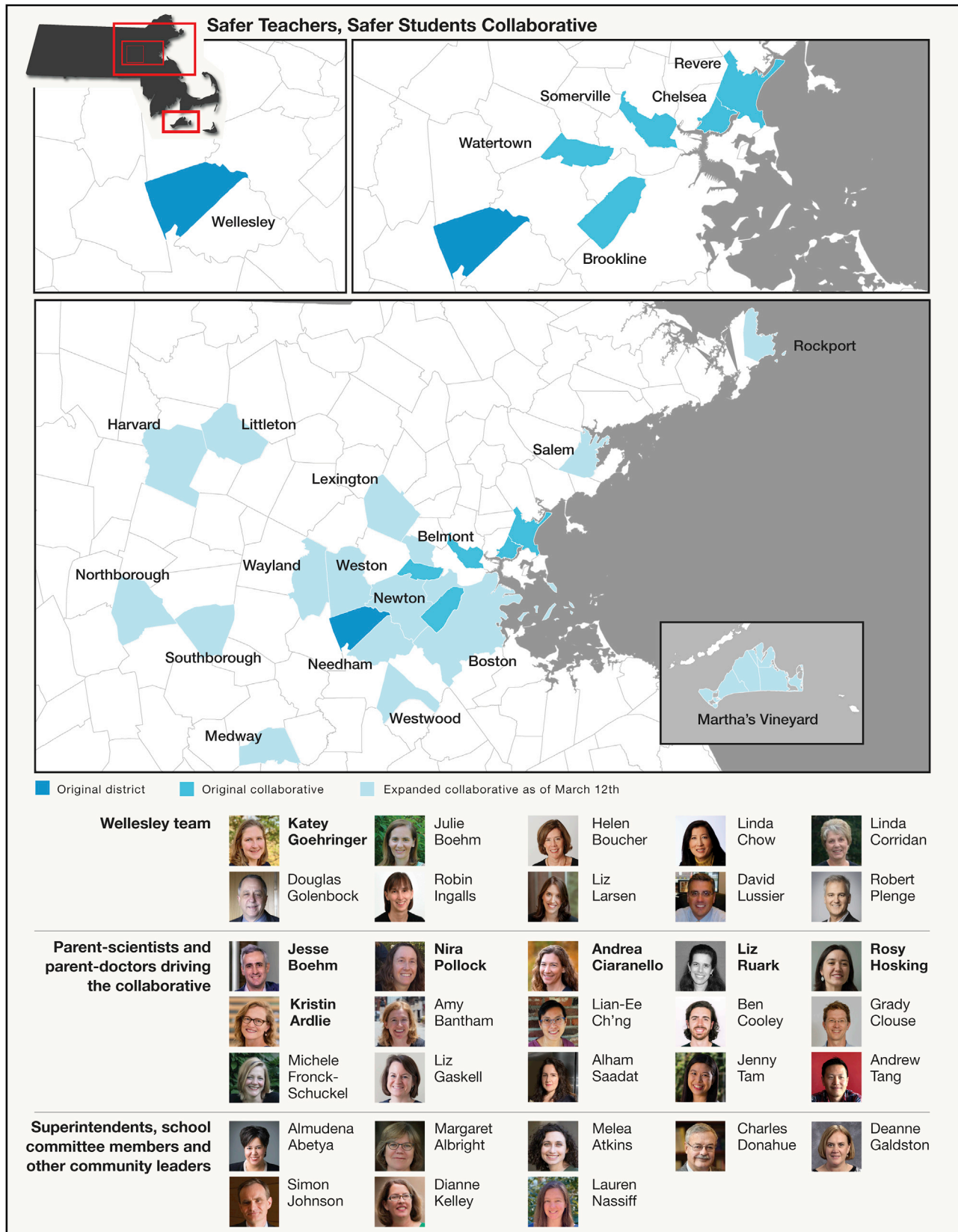
By December, leaders and parent scientists from over 20 additional districts had joined the Collaborative’s semi-weekly group teleconferences to share information and develop consensus strategy together. Our first Zoom call had six people. By December 12, we had nearly 100. Our work was featured on National Public Radio, in local news organizations and media outlets, *The Atlantic*, and *NBC Nightly News with Lester Holt*. Financial commitments from foundations came in to fully support the launch of testing programs in two districts who had been hit hardest by COVID-19 (Revere and Chelsea) as soon as they were ready.

There were still major challenges, and each district was necessarily carving its own path; we had healthy debates about the merits and drawbacks of different testing approaches and strategies. But we were all working together, through the fog and the complexity. Many had been stumbling, alone in the dark before we found each other in the Collaborative. We all believed in science, in data. And, we believed in teachers and public school kids. They were too important to be left behind.

Outcomes of the Collaborative

By early 2021, districts within the Collaborative had completed over 100,000 screening tests in public schools and had set up expedited testing access for symptomatic students and staff. We had demonstrated the operational feasibility of weekly surveillance. We had identified and vetted five high-quality vendors ready to serve, with adequate scale for all of Massachusetts. We had created a dashboard and peer-to-peer mentoring service enabling districts to easily help each other (see resource hub links on the Shah Family Foundation’s www.covidedtesting.com website).

We clearly demonstrated the public health value of surveillance testing in public schools. We were able to detect and quarantine over 100 asymptomatic cases of COVID-19. This system also enabled the early detection of at least one significant outbreak in a school office, likely preventing it from spreading further. (In addition, it identified a problem with the use of Plexiglas as a mitigation measure: the barriers disrupted office airflow, increasing the opportunity for transmission.)



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Most critically, surveys in several towns showed that COVID screening significantly reduced fear and anxiety among teachers (for instance in Wellesley, 82% of teachers said they felt safer with testing, as opposed to 12% feeling safe prior). We also began to reduce fear and anxiety among parents.

Finally, we demonstrated the strategic value of surveillance testing. We showed how a testing program and the actual collection of data could help productively resolve negotiations between districts and teachers' unions and enable a return to in-person learning. And we demonstrated how targeted actions could be taken in a data-driven manner.

Despite our efforts, equity and access for all remained (and still remains) a tremendous challenge. State and federal action was now needed.

From the Collaborative to a pan-Massachusetts effort

On January 8, 2021, almost exactly six months after Julie and I began our journey, we finally reached a key milestone.

That day, a state-wide solution for viral screening testing finally became plausible, thanks to the work of multiple organizations throughout Massachusetts, including our Collaborative. On January 8, the state Department of Elementary and Secondary Education (DESE) and the Executive Office of Health and Human Services (EOHHS) announced their intent to launch the first state-wide viral screening testing program open to every school in Massachusetts, to be financed through mid-April via state funds. Within two months, over 150 districts had joined in the program, including nearly 1,000 public schools.

As this piece comes to press, this pilot program is still playing out across Massachusetts. There is work to do to refine and perfect the detailed operational models, but one thing is clear: science is helping to rescue public schools. Data are starting to replace fear. Schools are reopening with SARS-CoV-2 testing as an added component of COVID mitigation strategy, providing assurance that we won't backtrack on all the progress that has been made.

We know that the rest of the nation is now watching: On March 17, 2021, the Biden Administration announced a \$10 billion commitment to K-12 COVID-19 surveillance testing in the United States, including \$207 million for Massachusetts.

The power of parent scientists

Scientists are truly capable of extraordinary things. We can create and manufacture COVID-19 vaccines in one year, send robotic rovers to Mars, and build particle accelerators to resolve the identities of subatomic species. However, many of us have another extraordinary job: we are parents and caregivers. We care about our kids, the communities that they are growing up in, and the educational systems and societal structures that support them and their development.

What I have learned from this COVID-19 testing adventure is that parent scientists have tremendous power to productively shape the future of our local communities and public schools, if we recognize how to wield this power with great care and with a collaborative spirit. We must respect the extraordinary professionalism of educators and school administrators. We must learn productive strategies to galvanize coalitions behind public policy decision-making, and we must recognize that these strategies are different than those required to build consensus among scientists.

Are there things I wish we'd done differently? Certainly. Despite many public schools in Massachusetts serving predominantly communities of color, we unfortunately did not engage a diverse enough cross-section of parent scientists in our group. For instance, we failed to engage parents from the African American community. Prioritizing more effort for targeted engagement and outreach could have made an even bigger impact.

Safer Teachers, Safer Students K-12 SARS-CoV-2 Testing Collaborative. Upper boxes: depiction of the growth of the Massachusetts Collaborative from one district (upper left) to the six founding districts (upper right), to all districts that were working together within the Collaborative by January (bottom). Bottom boxes: key individual and co-leaders (bolded) of the Collaborative. For a live map of all participating districts and information about their screening strategies and learning models, see www.ma-k12testingcollaborative.org.

I believe that our public schools have a tremendous, untapped resource sitting right under their fingertips. It's us: the parent-scientists who are ready to serve our schools with our expertise. Our role as scientists includes forging productive partnerships with educators and policy makers to solve vexing and urgent challenges facing our communities.

Our communities need us to do more than publish *Cell* papers. If COVID has taught us anything, it's that.

ACKNOWLEDGMENTS

I am deeply grateful for the entire Collaborative and in particular for the leadership team who helped me refine this piece. In particular, Liz Ruark, Rosy Hosking, Andrea Ciaranello, Nira Pollock, Kristin Ardlie, Alham Saadat, and Katey Goehringer. The author thanks Andrew Tang and Ben Cooley for assistance with the Safer Teachers, Safer Students K-12 SARS-CoV-2 Testing Collaborative map.