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2010: The Year of Advocacy



By Louise Kuo Habakus, MA and Mary Holland, Esq.

Homegrown, grassroots activism around vaccination choice is reshaping our society.

There are signs all around us that we're hitting a nerve. Public health officials are on the defensive, responding to allegations that H1N1 swine flu was a fake pandemic. Parents are outraged over mounting state vaccine mandates. After witnessing New Jersey Governor Chris Christie's victory on the heels of his campaign promise to support vaccination choice, politicians are courting parent support groups. Healthcare workers, buoyed by union support, rallied in Albany, New York, last fall against state-mandated flu vaccines, inspiring colleagues worldwide to reject the shots. Beleaguered pediatricians are accommodating concerned parents with alternative vaccine schedules.

It all starts with each one of us, in the privacy of our personal space, and in the public domain of our community and professional lives. As individuals and guardians, we are mustering the courage to resist governmental and institutional pressure in the face of impossible vaccination choices.

WHAT IS ADVOCACY?

Advocacy is pursuing social change. It's influencing outcomes within political, economic and social systems and institutions that affect lives. **Advocacy is the place where education meets passion and we**

are moved to act. Some of us come by our passion through the school of hard knocks. Some of us are inspired by the stories of others. The result is that we get involved. When we come together around shared goals and work side by side, we become brave, we create community, our voices are heard, and we attract others to our cause. When we engage in advocacy, we're walking the walk and doing our part to make the world a better place.

Advocacy is an umbrella term for activist efforts people conduct in good faith around a specific set of issues. Activism starts with a single act. It can be a decision quietly and proudly made. It can be an explanation given or withheld. It can be a product or service bought or refused. It can be a bumper sticker, a lawn sign, a car magnet deliberately placed. It can be a donation thoughtfully offered. It can be a flyer posted or a business card shared. It can be a movie viewed, a lecture attended, a petition signed. It can be a meeting organized. It can be a banner held high, standing in our integrity at a rally.

It can be very difficult to help people understand our issues. In response to the misery of others, it's human nature for well-intentioned people to offer consolation but then turn a blind eye. This doesn't make them heartless. Truth be told, none of us could function if we opened ourselves to the plight

of others all the time. But there's a lesson here. The message that unites us with others is one that successfully communicates how the issue of vaccination choice is in fact *all about them*.

People without vaccine injury are starting to ask questions about the safety of vaccines, autism incidence, and whether we are being told the whole story. Over the past 2 years, Louise has been giving community talks and conference presentations about individual rights and the connections between vaccines, the environment, and children's health. People from varied backgrounds attend. They bring friends and loved ones. They listen. They are environmentalists, health workers, libertarians, senior citizens, military families, immigrants, and advocates for parental, religious, and human rights. They represent geographic, religious, and socioeconomic diversity in our country. And they are all starting to question the wisdom and consequences of having the most aggressive childhood vaccination schedule in the world.

Americans have an expectation that we get to make the decisions that deeply affect our lives. The message of individual freedom transcends political party lines and resonates deeply in our country. On the heels of a dubious swine flu pandemic whose vaccine was resoundingly rejected, the public is ready – even eager – to talk about the U.S. approach to vaccines and public health.

SCIENCE, LAW AND POLITICS

We are told that vaccines are nothing short of a public health miracle . . . They have saved millions of lives . . . They are safe . . . If people stopped vaccinating, deadly diseases would return and spread . . . The fight for vaccination choice is an act of social irresponsibility. Mainstream science says vaccines are good medicine. How do I argue with my doctor, with the school nurse, *and* with my government if I want vaccination choice?

Here's what you need to know, no matter what you hear: *the jury is still out*. There are significant concerns about the scientific studies conducted to-date and the conclusions drawn. Suffice it to say that there's a lot at stake in managing the message and gatekeeping the facts. We strongly support scientific efforts to understand the long-term health effects of lifelong vaccination, including the connection to autism and other neurological and autoimmune disorders. But

an exclusive focus on science is not enough.

Most of us don't realize that vaccination laws rest on the concept of public health emergencies. States have *police powers* to enforce vaccine mandates based on the precedent of a Supreme Court case – *Jacobson v. Massachusetts* – dating back to 1905. That's more than 100 years ago. We don't need to tell you that life was very different then; it was a time that predated antibiotics, widespread sanitation and hygiene, and the international legal standard of informed consent. One might reasonably question today whether there is a sufficient public health emergency that our state governments should wield police powers to mandate upwards of 45 doses of 14 different vaccines for children as a requirement of school admission. This is a debate worth having. But it confuses the matter at hand. The bottom line is our right to choose.

THE SANCTITY OF PERSONAL SPACE

Our personal space is as personal as it gets. Personal rights are the rights that a person has over his own body. Among these are the associated rights to protect and safeguard the body. The right to personal security, the right to individual autonomy, the right to make life-and-death decisions for ourselves and our children – these are fundamental, universal rights. These are our most basic rights, and violation of our bodies is the ultimate intrusion. It can't be stated any more plainly than that. The inalienable rights of life, liberty, and personal security are foundational principles of the United States of America. They are in the United States Bill of Rights, the first ten amendments to the Constitution, which protects individual rights of all citizens. The Universal Declaration of Human Rights states these same principles and is signed by nearly all nations of the world. These rights form the basis of our social contract: what we owe each other, and what the nation owes us. They strike at the heart of our humanity. They must be protected.

Our individual rights do not hang in the balance of scientific dispute. Science may or may not prove potential links between vaccination and chronic disease. Regardless, we have the right to be left alone, and vigilance is the price of freedom. To relinquish fundamental rights is to alter the very landscape of freedom in our country.

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THE AMERICAN RALLY FOR PERSONAL RIGHTS

We are readying our rallying cry in the heartland of the country! The inaugural American Rally For Personal Rights will be a joyful affirmation of our universal rights, including the right to personal autonomy and vaccination choice. The rally will take place on Wednesday afternoon, May 26, 2010 at Grant Park in downtown Chicago. We will stand together in support of our rights to life, liberty, and personal security, including the right to choose if and when to vaccinate.

The symbolism of Grant Park will not be lost on Americans. Two years ago, standing with nearly a quarter million people, President-elect Barack Obama galvanized the entire world with his victory speech and entered American iconography on a wave of hope and the promise of change.

This spring, Americans will send yet another powerful message from Grant Park. The United States of America is a beacon of freedom and individual rights the world over. Citizens of the United States demand freedom and rights at home. We demand the right to make the vaccination decisions that affect our lives and those of our children.

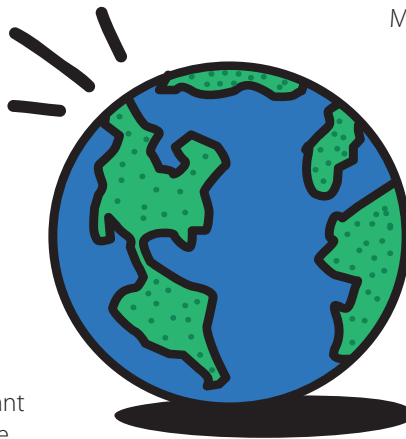
CAPTURING THE MOMENTUM

Participation in a public rally can be one of life's memorable experiences. There are not many times in our lives when we have a visible, dramatic, and powerful opportunity to join with others and proclaim our rights on a public stage. When an issue has resonance, the imagery and chants are televised across the country, and the themes are burned into our consciousness.

A rally is like a shooting star. It burns brightly and then it's gone. What matters most of all is what happens in the days and months after a rally. It's the hard work each of us does to capture the energy, intention, and passion from the rally and translate it into action. How do we get people talking about the personal right to vaccination choice in living rooms across the country? How do we keep the dialogue going?

WE NEED TOOLS!

Let's be honest. It's a tough topic to discuss.



Many of us struggle in those brief moments when we have the opportunity to say something. Maybe it's with our child's pediatrician, a neighbor at a cocktail party, or our sister-in-law who happens to be a school nurse. The words don't form into coherent sentences. The heart races as we imagine all the eyeballs staring us down.

Non-vaccinators put everyone at risk. Our personal vaccination decisions quickly become society's business. The subject is controversial, polarizing, and at times downright uncomfortable. So what do we do? How do we initiate an open, non-judgmental conversation about vaccines?

Just do it? To fuel the courage, we need to prepare a bit. We need tools! While it is tempting to wait for the next rally or for a high profile spokesperson to deliver the message for us, the power of our movement will come from each of us doing our part. And our movement will build as we share our work with each other, in the spirit of open source collaboration. We have started to tread these waters, learning some lessons along the way. And we're offering up our resources to you.

"MEETING-IN-A-BOX"

We plan to unveil a collection of tools at the Autism One/Generation Rescue Conference in Chicago next month. We're calling it "meeting-in-a-box" to support your efforts to take the message *on the road*, wherever it may lead. Start small and intimate, at your best friend's house or your church Bible study group. Build up to larger support group meetings or the entire PTA in the school auditorium. You'll be armed with PowerPoint slides, talking points, frequently asked questions, meeting guides, organizing templates, video support, DVDs to hold movie screenings, articles, handouts, business cards, and even flash cards for those spontaneous occasions when you need on-the-spot support.

You'll have a chance to experiment with these tools during the Advocacy Track "boot camp training" at the conference. We'll deliver the presentation and then teach you how to do it, via facilitated breakout sessions and simulated role plays. Experienced activists will act out



scenarios with board certified pediatrician Larry Palevsky who understands and supports parents' need to have vaccination choice. In a treat for conference-goers, he will also play the role of board certified pediatrician Harry Palevsky, his misguided twin brother, who fires patients who refuse to vaccinate.

You can receive a version of the same PowerPoint presentation that has been road-tested and delivered nearly 50 times in the past two years, in venues both large and small, to people with a wide variety of beliefs, concerns, and backgrounds. Every fact is sourced and referenced. The materials have been reviewed by experienced physicians, scientists, attorneys, and activists so you can have confidence in the accuracy of your message. The tools are for your own use, in the best way you see fit, in your communities. There's no obligation to deliver any specific information, in any standard format. There's no new organization to join. The goal is to pass the message on. Our numbers are large and much greater than we realize. By working together to start a conversation, we will build a national personal rights movement for vaccination choice.

We're hoping to motivate people to work together. Not everyone is comfortable with public speaking. A wide variety of skill sets is

needed to gain momentum. These include event planning, graphic design, marketing, social networking, media relations, community outreach, and fundraising. What do you love to do? Whatever it is, we need you!

SHARE YOUR VOICE, CHANGE THE WORLD

The first step is the hardest. People appear unfriendly. Your voice eludes you. The knot in your stomach won't go away. Here's what you need to do. Find a friend. Stand next to just one person who feels the same way that you do and a remarkable thing happens. You share the load. You feel a bit braver. One plus one is more than two. You host your first event. And then you're off to the races. You will find another friend, who will bring a friend. You will host another event: more friends. You will then find your voice in a sea of other voices.

Above all, remember Margaret Mead's words: *Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.*



AUTISM MOTHERS



West Tennessee www.yatesfoundation.org



Idaho



Pleasanton, California

"Our message is clear: we stand united as Autism Mothers; we are a powerful alliance and we do deliver where governments have failed."

Polly Tommey



Eugene, Oregon