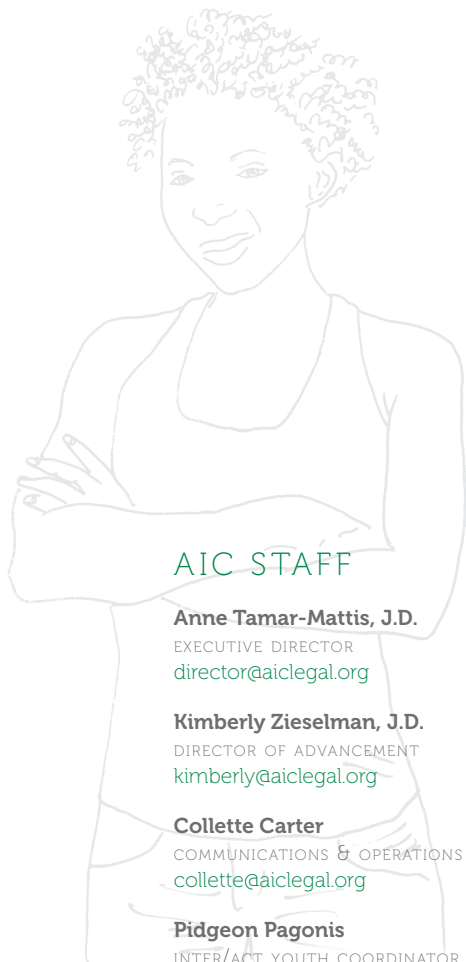




advocates for  
informed choice

# 2013 Annual Report



## AIC STAFF

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**Pidgeon Pagonis**

INTER/ACT YOUTH COORDINATOR  
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## CURRENT BOARD

Sean Saifa M. Wall, President  
Emily Doskow, J.D., Treasurer  
Julie Greenberg, J.D., Secretary  
Katie Baratz Dalke, M.D.  
Arlene B. Baratz, M.D.  
Mani Bruce Mitchell

## BOARD EMERITUS

THANK YOU FOR YOUR COUNSEL  
AND SERVICE!

Hazel Glenn Beh  
Nancy Ehrenreich, J.D.  
Peter Trinkl\*  
Emi Koyama\*  
Jim Lake\*

\* Transitioned off of the Board  
at the end of 2013.

# Looking back & moving forward: *A message from our Executive Director*

2013 has been our year of building. When AIC began in 2006, our vision for improving the quality of life for children born with intersex conditions or DSD encompassed a great deal. Here we are seven years later with the strong support of our community, engaged for the long haul, and successfully moving forward toward a society where our children have agency in determining their future.



Along our journey this year we deepened our partnerships with intersex organizations and activists around the globe, celebrated the vibrancy of our work on a local, national and international scale, and committed ourselves to reflecting the range of diversity within our community and supporters. Most notably, we filed important litigation

on behalf of M.C., a child born with an intersex condition, whose options to make decisions about his body were taken from him before he was 16 months old. These accomplishments can be felt in strong statements from human rights bodies across the globe against medically unnecessary and nonconsensual normalizing procedures, and an encouraging number of hospitals and health organizations reviewing their policies in light of current information.

We grew in staff, hiring Kimberly Zieselman as our Director of Advancement, Collette Carter as Communications and Operations Manager and Pidgeon Pagonis as our Inter/Act Youth Coordinator. We also grew in programming, presenting our work at conferences, schools and events, seeing the impact of our work both in the media and in increased requests for our presentations. But we still need you! Now is the time for us to reflect on how we leverage our opportunities and keep our forward momentum. This isn't going to be easy but it's worth the work.

When you read through the accomplishments of the past year (and I'm pleased to say there are many to report on!), please know that it is in large part your confidence and willingness to step-up on behalf of the rights of an otherwise invisible population that has kept AIC's leadership and me moving at full speed. Together we are improving the future for these special children.

Thank you for all you do for our children.

**Anne Tamar-Mattis**  
EXECUTIVE DIRECTOR

# Reflections on history in the making

In review of 2013, AIC is taking on discrimination and injustice step-by-step, case by case. As the lawsuit in South Carolina is moving along, we are celebrating small victories not only impacting state and federal law, but also bringing awareness of bodily integrity as a human rights issue.

We represented this year at the Third Annual International Intersex Forum in Malta, hosted by ILGA (International Lesbian and Gay Association) with support from the government of Malta, and were joined by some of the most influential intersex activists in the world. At this meeting, we forged stronger alliances and highlighted key issues that are critical to our sustainability as a movement.

At home, we are shifting gears to accommodate new voices and experiences on our board while honoring those who have helped to build AIC from the ground up. I would like to take a moment to thank Emi Koyama, Peter Trinkl, and Jim Lake for their hard work and contributions that have left an indelible mark on AIC. I would also like to thank Katie Baratz Dalke, who for three years, governed as board president as AIC grew from a small organization to an organization that is expanding its international reach.

As we move ahead in 2014, we need the support and financial contributions of our allies to affect greater change in this world as we create safer spaces for intersex children and adults.



photo by Dottie Suggs

**Sean Saifa M. Wall**

BOARD PRESIDENT

## Building community



photo by M. Carpenter, Oii Australia.

*Attendees at ILGA's Third Annual International Intersex Forum.*

Representing the interests of intersex/ DSD children and families, AIC expanded our reach significantly, bringing our experiences and analysis to key collaborations, conferences, events, movements and human rights institutions across the globe. We provided training to over 275 medical providers and over 100 attorneys; legal services to over 30 intersex people and their families; as well as education and guidance to over

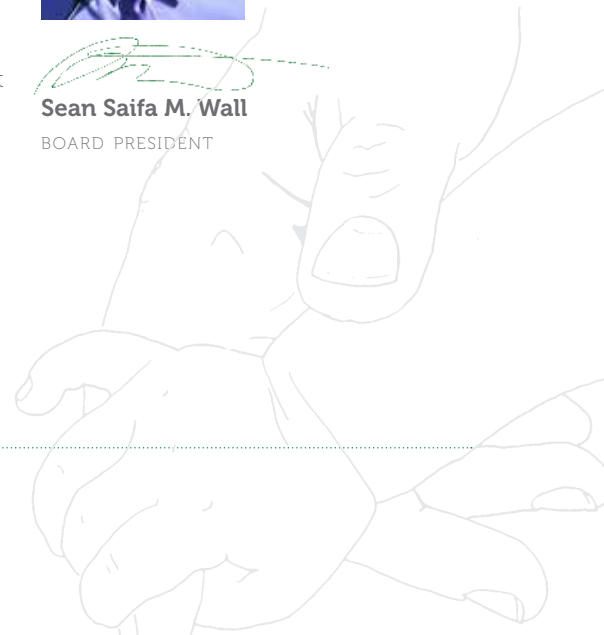
40 parents of children with DSD, over 130 intersex adults and youth, and over 450 others at speaking engagements.

Key highlights of our 2013 successes:

- \* Testimony provided to Inter-American Commission on Human Rights hearing in Washington, DC, along with other intersex activists from across the Americas, to begin a process considering the best practices for the treatment of infants and children with intersex conditions.
- \* AIC's testimony which informed the UN Special Rapporteur on Torture's statement on Torture in Health Care garnered response from the International Group of Pediatric Endocrine Societies, acknowledging a need to value input coming from international governance, human rights bodies, support and advocacy groups.
- \* Keynote address of 17th annual Androgen Insensitivity Syndrome –

Disorders of Sex Development Support Group (AIS-DSD) conference in Boston, MA, given by Executive Director Anne Tamar-Mattis.

- \* Participation in a National Institute of Health (NIH) Listening Session in Washington, DC to advance the health of LGBTI individuals to determine the highest priority research areas in LGBTI health.
- \* Published a joint statement with the AIS-DSD Support Group reflecting on the impact of Germany's new third-gender birth certificate law.
- \* Participation in the Third International Intersex Forum and public statement, supported by ILGA and ILGA-Europe and activists representing thirty intersex organizations from all continents.
- \* Presented at a highly-regarded west coast children's hospital about the law and ethics of infant genital surgery in light of the *M.C. v. Aaronson* case.



# Changing lives

2013 was a significant year of growing and staffing and programs at AIC. The visibility of the lifelong impact of medically unnecessary surgery, and of AIC's work towards a holistic approach to informed consent for children and families affected by intersex conditions or DSD has increased across communities, movements and regions. AIC's Intersex Awareness Day visibility campaign and summer assessment from our stakeholders identifying the top five priorities for DSD care are successes that reflect the critical work of all our AIC supporters and our commitment to the rights of intersex/DSD children. The impact of AIC's programming for 2013 is something in which we can all take pride.

## Project integrity

Project Integrity is AIC's impact litigation and medical education program. Through consultations and training to healthcare providers, publishing in the medical, legal, and bioethics press, and advocating for our constituents' legal rights, we work to ensure that children with intersex conditions or DSD have the same protection for their rights that all other people receive in hospitals, doctor's offices, schools, sports, research activities, and everywhere else.

- \* On May 14, 2013, Advocates for Informed Choice, The Southern Poverty Law Center, and pro bono

counsel for the private law firms of Janet, Jenner & Suggs and Steptoe & Johnson LLP filed a lawsuit against South Carolina Department of Social Services, Greenville Hospital System, Medical University of South Carolina and individual employees for performing irreversible and medically unnecessary surgery on "M.C.," an infant who was in the state's care at the time of the surgery.

- \* On August 22, 2013, U.S. District Judge David C. Norton of the South Carolina Charleston Division denied a motion by the defendants to dismiss the case. The federal court concluded that medically unneces-

sary sex-assignment surgery on a child with an intersex condition could be a violation of the child's constitutional rights.

## Resolve

By inviting individual providers and professional institutions to listen to intersex adults and apologize for the harm suffered as a result of medical treatment, Resolve offers a radical model of equal relationships between doctors and patients. We recognize patients as valuable sources of expertise, and doctors as only human. More importantly, we encourage healing on all sides that will improve care for future children. For more information on Resolve contact [kimberly@aiclegal.org](mailto:kimberly@aiclegal.org).

- \* Updated the Resolve Tool Kit to include samples of draft letters and responses from health institutions.
- \* Continued recruitment and development of Resolve participants using social media and by hosting letter writing workshops.

photo by Arianna Davis



*Morris Dees and David Diniell of Southern Poverty Law Center; Anne Tamar-Matts of AIC; Mark and Pam Crawford; Alesdair Ittelson of SPLC; Will Ellerbe and John Lovi of Steptoe and Johnson LLP; Ken Suggs of Janet, Jenner, and Suggs; and Kristi Graunke of SPLC.*

[aiclegal.org](http://aiclegal.org)



**#justice4MC**

Designed by Eden Atwood



## Intersex Awareness Day 2013



Meme for 2013 Intersex Awareness Day by Inter/Act member Alice Alvarez.

### Inter/Act

Inter/Act is a place for young people with intersex conditions or DSD from across the globe to come together, express themselves, and unite their individual stories to develop a voice for a new generation. This is where our young people say what they think about their lives. They come from every background with different perspectives and experiences. For more information on Inter/Act contact pidgeon@aiclegal.org or visit the youth blog at: [www.interactyouth.tumblr.com](http://www.interactyouth.tumblr.com).

- \* Pidgeon Pagonis, AIC's then Youth Leadership Intern, became the first young person to give expert testimony at the Inter-American

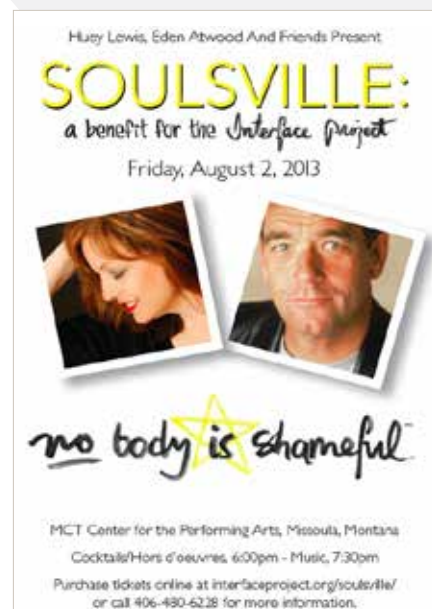
Commission on Human Rights in March of 2013.

- \* As Inter/Act's new Youth Coordinator, Pidgeon also gave a keynote speech at Trans, Gender Non-Conforming, Intersex Freedom Rally in Chicago's Union Park.
- \* Inter/Act created social media memes to spread awareness about the ideas and myths that often circle intersex bodies and lives in addition to sharing personal reflections and poetry for Intersex Awareness Day.
- \* Coming In 2014, Inter/Act youth members will participate in the first conference ever led by youth with intersex conditions.

### The Interface Project

AIC also served as fiscal sponsor for an exciting new volunteer program, The Interface Project. The Interface Project's mission is to gather and share personal stories of people living with an intersex condition or DSD to spread the message, "No Body Is Shameful.™" For more information or to view Interface Project videos visit: [www.interfaceproject.org](http://www.interfaceproject.org).

- \* Produced "Soulsville": A project benefit concert featuring Huey Lewis and Eden Atwood in Missoula, Montana. Reaching over 300 people, the evening provided education on issues faced by intersex people.
- \* Volunteer Jim Ambrose appeared as a guest on BBC Radio with Dawn Rachel Vago and Holly Greenberry of Intersex UK.
- \* Featured coverage of Interface work on dot429 the largest Lesbian, Bisexual, Gay, Trans, and Ally Professional Network.



Program cover from Soulsville event.

photo courtesy of the Southern Poverty Law Center

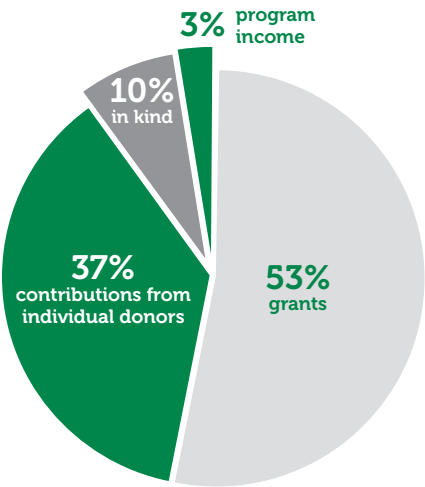


Pam and Mark Crawford.

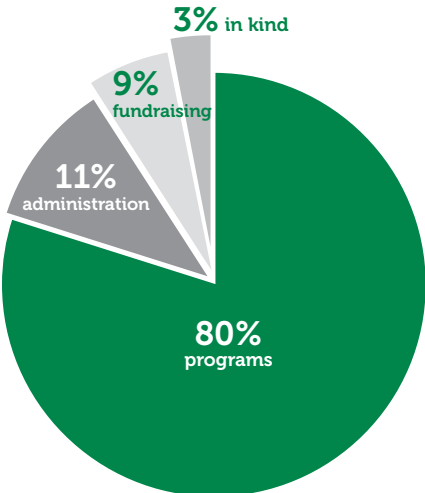
### Thank You "M.C." and Crawford Family

Our client "M.C." and his parents, Pam and Mark Crawford, have profoundly impacted us with their support for AIC's overall work, confidence and collaboration with the legal team as part of the Project Integrity lawsuit and their abundant dedication to advocating for their child's right to an open future. We thank you for all the ways you have put yourself into this work and dedicate this, our second annual report, to you and the legacy that you help continue.

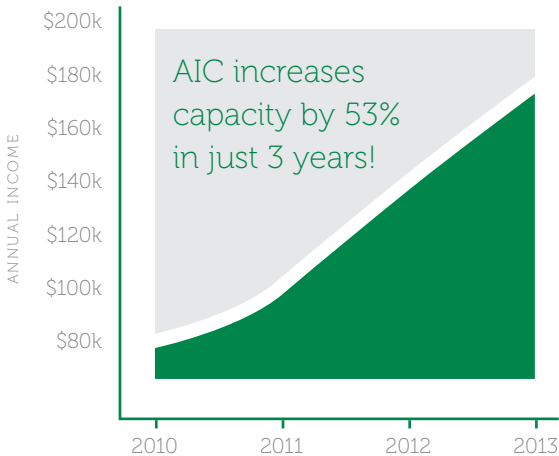
OUR CAPACITY AND IMPACT CONTINUE TO GROW AT AN IMPRESSIVE RATE WHILE MAINTAINING A LEAN OPERATING BUDGET.



2013 income by revenue type



2013 expenses by area



Because of your belief in us, we effectively:

- Increased our staff capacity from 1.5 positions to supporting two full-time and two half-time staff.
- Generated over \$70,000 in individual donations (our highest total ever - thank you!) A 60% increase compared to 2010.
- Met our goal of 100% participation in fundraising among AIC's Board of Directors who jointly secured over \$20,000 in resources.
- Partnered with new foundations who share our vision, bringing AIC's foundation support to over 50% of our annual income.
- Increased our web presence with regularly published blog articles and nearly doubling AIC's number of loyal Facebook followers.

AIC supporters are essential!

You, our AIC supporters are crucial to our capacity to fight for the rights of children with intersex conditions and DSD. In 2013 you rose up in support of #justice4MC by pledging your support of the Crawford family and our legal team, and making extra donations to sustain the fight. AIC is extremely grateful to each of our individual supporters and foundation partners. We need your help more than ever to maintain and grow our impact both in the U.S. and globally.

THE INTERFACE PROJECT HAD AN EXCEPTIONAL FIRST YEAR, BRINGING IN OVER \$40k IN DONOR SUPPORT.

# Thank you to our supporters

Thank you to everyone who said “yes” to taking action on behalf of our special children by making a gift to AIC. The investment and diversity of our donors, who come together to support our mission, create a crucial foundation for AIC and the future of our community and our children. It is a huge point of pride for us that the committed support we receive from our donors continues to be a central resource that sustains our work.

## “Champions”

Our special team of donors who made 2013 gifts of \$900 or more

Anonymous  
Arlene B. Baratz, M.D.  
Adrienne Carmack, M.D.  
Pamela and Mark Crawford  
Milton Diamond, Ph.D.  
Tiger Devore  
Emily Doskow  
Jim Dykes  
Julie Greenberg  
Bo Laurent  
Mano Marks and Tracy Schmidt  
Rebecca Mascott  
Taylor Mattis  
Meg Robertson and Sheila Jaswal  
David Cameron Strachan  
and Peter S. Tannen  
Barbara B. Taylor  
Karen Walsh  
Wazir Woods

## “Guardians”

Our donors who made 2013 gifts of \$250-\$899

Anonymous  
Anonymous  
Ray Bernstein  
Rob and Wendy Blair  
Frank and Michele Brown, *In Honor of Katie, Arlene and Mark Baratz*  
Katie Baratz Dalke, M.D., and Sam Dalke, Esq.  
Ellen Feder, Ph.D.  
Judith Geizals, Ph.D.  
Jane Goto, *In Honor of Kimberly Zieselman*  
Janet Green  
Herma Hill Kay  
Charles Mascott  
Alan Meisel, *In Honor of Arlene Baratz*  
Sherri G. Morris  
Shirley Perreira, *In Honor of Renee Winton*  
Tracey Prazer  
Linda Gebroe and Rebecca Silverstein  
Terry Reed, *On Behalf of GIRES*  
Elizabeth Reis  
Peter Trinkl  
Lena Turner  
Sean Saifa Wall  
Alexandra M. Walsh, M.D., MSPH  
Reid Williams  
Philip Yenawine  
Dana Zzyym

## Previous funders who have supported AIC

Ms. Foundation  
Ashoka Changemakers  
Echoing Green  
Astraea Lesbian Foundation for Justice  
Equal Justice Works  
Gill Foundation

## The funders that help catalyze our work:



## Special thanks to our amazing volunteers:

- \* **Our Key Volunteers and Legal Interns:** Courtney Fraser, Bo Laurent, Sasha O'Malley, Christina Winship and Christa Whitlow; and from the Sexuality and Gender Law Clinic at Columbia Law School, Henri Benaim, Gill Dingle, Larissa Eltsefon, Andy Kravis, Laurah Samuels, and Prof. Suzanne Goldberg.
- \* **The generous Pro Bono Legal Service Providers:** John Lovi and William Ellerbe of Steptoe and Johnson LLP, and Kenneth Suggs of Janet, Jenner & Suggs, LLC.
- \* Alesdair Ittelson, Kristi Graunke, David Dinielli, and Morris Dees of the **Southern Poverty Law Center**.



photo by Holly Greenbery

*Jim Ambrose, Pidgeon Pagonis & Sean Saifa Wall at the International Intersex Forum, Malta.*

## You can help advance the intersex and DSD movement

You have helped AIC become a thriving and impactful civil rights leader—and we thank you! We know how important protecting our children is to you and there are many opportunities for you to continue taking a stand:

- \* Visit our website and sign up to support AIC and justice for M.C.
- \* Put Inter/Act's "What we wish our doctors knew..." brochure in the hands of your medical providers (download available at [aiclegal.org](http://aiclegal.org)).
- \* Encourage your friends and family to donate to AIC in honor of your birthday or a special occasion through social media.
- \* Visit our website, join AIC's mailing list and stay updated on our work.
- \* If you are a person with an intersex condition, consider participating in Inter/Act, Resolve or The Interface Project.
- \* Share this report widely and talk about why intersex rights matter to you.
- \* Put AIC on your giving list: make a one-time gift today or join our monthly donors to help AIC maximize impact. Your donation of any size helps! Mail your check made out to "Advocates for Informed Choice" to PO Box 676, Cotati, CA 94931, or donate at [aiclegal.org](http://aiclegal.org).

- \* Ensure your legacy continues to support AIC in our fight for the rights of children born with intersex conditions by including AIC in your estate plan.

For more information, or if you would like to contribute in another way, please contact Kimberly Zieselman, Director of Advancement, at [kimberly@aiclegal.org](mailto:kimberly@aiclegal.org).

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