

# What we can learn from 15 brave stories of real European intersex lives

[Blog](#), [Health](#), [Intersex](#)

“Sometimes it is necessary to speak clearly from a very personal or intimate point of view,” says intersex activist Ins A Kromminga, co-founder of [OII Europe](#) and illustrator of ‘#MyIntersexStory: Personal accounts by intersex people living in Europe’. The 15 beautifully illustrated, but often harrowing stories in this groundbreaking publication speak “a clear and frank language of things that are often hard to speak about”.

For intersex people, whose bodies are all too frequently referred to only in medical terms, there is great power in being able to tell their stories in their own words. This was one of the aims of ‘#MyIntersexStory: Personal accounts by intersex people living in Europe’, a book with 15 frank and unflinching testimonials, published this year by OII Europe.

Based in Berlin, [OII Europe](#) is the umbrella organisation of European human rights-based intersex organisations. It works for the full implementation of human rights, bodily integrity and self-determination for intersex people and is a member organisation of ILGA-Europe.

The illustrations by Ins A Kromminga in ‘#MyIntersexStory’ portray people who could be your neighbour, your friend, your co-worker, while at the same time showing that intersex people are resilient, strong and beautiful.

At the same time, the drawings are illustrative of a huge issue for intersex people that still remains over a quarter of a century since the first historic demonstration by intersex activists. Find out how in this powerful interview.

## **Hi, Ins. To begin with, tell us how the #MyIntersexStory project began?**

The original idea came from a brochure we created within a project of a local and national organisation in Germany, at the time when the first study on feminising and masculinising surgeries on intersex children of the age 0–9 was published. The study showed that these intersex genital mutilations (IGM’s) continued, despite other claims from the medical field. We wanted to provide an additional resource to give the statistics in the study a human and relatable perspective.

In the brochure we deliberately refrained from reproducing medical and diagnostic descriptions to explain certain operations and diagnoses, and instead have intersex people describe what happened to them in their own words. The brochure contained short quotes by intersex people and their experiences of how the medicalisation had affected, and continued to affect, their lives, combined with colourful graphic representations of individuals in everyday situations.

The German brochure initialised the idea for a similar publication in English with a European scope of testimonials, which would include artwork that visually corresponded with the stories.



#MyIntersexStory. All illustrations by Ins A Kromminga

### **How did you creatively experience the process of illustrating such incredibly personal stories?**

The process took quite a long time and changed several times in terms of how to approach the testimonials from an artistic standpoint. The project grew bigger over a period of almost three years of developing and finishing the final book. We included additional testimonials, and the images became much more intricate than originally intended.

The people who contributed to this project are incredibly brave and we thank each and every one of them for agreeing to share their stories. Without their willingness to put those stories on paper — which also includes reliving the experience of IGM to a certain extent — this book would not have been possible.

As an intersex activist and as a professionally trained visual artist, these two aspects in my life always competed

with each other for time and attention, and the best moments for me are when I can combine the two. This was the case when I created the images for ‘#MyIntersexStory’. As I point out in the introduction, I did not want to ‘illustrate’ one specific person or story, but instead have the images show people who could be anyone in our society — a neighbour, a family member, an old friend from school. I also wanted to show that intersex people are resilient, strong and beautiful.

At the same time, and in a more subtle way, using illustrations also shows a remaining big issue for intersex people. The majority still live in the closet and are afraid (often with good reason) to show their faces and speak up in a society that continues to discriminate and pathologise intersex realities, and where legal protection is non-existent in most countries.

That’s why not one person in the images and stories is recognisable or identifiable. The personal accounts speak a clear and frank language of things that are often hard to talk about. They are very personal and subjective, but, as in the text in the book by Janik Bastien Charlebois points out, they are the forefront of intersex activism and precious and valuable forces in our fight for dignity.

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Ins A Kromminga

**In the introduction you write about stepping “out of invisibility”, but also “deciding on what and how much we want to share”. What obstacles does the intersex community face in finding the right balance between telling and keeping boundaries, which other communities may not face?**

To share one’s personal account of being intersex can be difficult. There continues to be many misconceptions on what the term intersex means and who the people behind that word really are. And when people learn of the many ways one can be intersex, it quickly can become overwhelmingly complex, and at the same time boringly normal.

Since the issues intersex people experience often have to do with how our bodies are perceived by others, specifically the medicalisation of our variations of sex characteristics and the human rights violations they entail, things get very personal and private quickly. Therefore, as intersex activists we have developed a sensitive language to speak about our experiences without disclosing aspects that should remain every person’s individual choice to reveal. Sometimes it is necessary to speak clearly from a very personal or intimate point of view, but how much, or in what depth, everyone needs to decide for themselves, depending on the context. For example, I would speak differently with a close friend or partner about things than I would on a public panel.

Most of us have experienced such an intense level of taboo and stigmatisation, often from a very early age, that coming out can feel like liberation from a heavy blanket of silence and invisibility. The sheer need to communicate and put into words what otherwise had no concept or language, can lead to an urge to not holding back any details, in ways that might not always be good for ourselves or others. As intersex people we have to carefully re-learn what is necessary to talk about, and how much we want, or have to, share with the world.

**Is the personal political?**

Yes. Longer answer: the phrase that stems from the feminist and radical feminist movements is also true for intersex people. Fragmented and isolated under a medically prescribed taboo and the stigmatisation of bodily difference, every individual intersex person has to first do the archeology of their own story that lies buried under disinformation and silence.

The second step to realise that this very personal experience was not indeed as individual as it initially might have seemed, but instead is part of a systemic medical protocol that had spread globally by the end of the 1960's. Intersex variations are still considered a disorder of sex development in the newest edition of the International Classification of Diseases (ICD-11), even though over 70 United Nation Treaty Bodies and many other human rights institutions have clearly identified and condemned the human rights violations and abuses intersex people face in most countries, which often happen within medical settings.

Intersex bodies, similarly to women's bodies or the bodies of people with disabilities have been historically medicalised, objectified, ostracised and marginalised. We are all survivors of a heterosexist and patriarchal system that still does not want to loosen its grip and reflect and share the world with all human beings.

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### **What social change can be achieved through art and personal stories that cannot be achieved through advocacy work?**

In the end we want to change our societies so that intersex people can enjoy their human rights just as every other person should be able to. In order to get there, there are many ways to inform, educate, raise awareness, advocate, consult and engage, and OII Europe believes in the benefit of using them in all their diversity.

In our eyes art and personal stories open other additional channels of empathy; they make people understand or relate on a more direct and emotional level. I think we will always need both, advocacy and legislation that will protect the rights of people, but also a change in culture, also through art, that speaks about the core of what it means to be human and how intersex people are part of humanity and our societies.

### **Some of the protagonists of the book are over 30, 40 and 50 and had surgical intervention when they were babies or children. Have the protocols in European health systems got better ever since? What has changed — or has not — for that to happen?**

Since the first intersex people rallied in front of a medical conference in Boston 24 years ago, the medical field has adjusted and changed its approaches. Unfortunately their adjustments, with a few exceptions, mainly focus on reframing the issue and changing terminologies, not stopping the interventions of unconsented cosmetic surgeries and other medical treatments, as recent studies from Germany show.

Those interventions are often based on social constructs and biases. Regarding people born with variations of sex characteristics, the sole reason non-vital medical interventions, i.e. cosmetic feminising and masculinising operations, are performed is to make us look and function as (heterosexual) boys and girls, and later as men and women who will engage in heterosexual classical penetrative (penis-in-vagina) intercourse.

That this is not working should be clear after almost 30 years of criticism by intersex activists. The norm of the heterosexual and sex-binary human is one we have to overcome. Our world is much more colourful and diverse, and we all need to cherish it, not fear or regulate it.



#MyIntersexStory. All illustrations by Ins A Kromminga

**Some words that are repeated across the 15 stories are very strong: “object of science”, “lack of information”, “medical violence”, “mutilation”, “body betrayal”. What words would you like to be shared by the intersex community instead of these?**

Integrity, dignity, truth, intact intersex generations, autonomy, decency, informed choice, intersex-centered health care, celebrating diversity, intersex is beautiful, loving our bodies, exploring our full potentials, hermpower, hermlove, hermhugs, too cute to be binary... I shall collect more of those!

### **How did you first get involved with OII Europe?**

I am one of the co-founders of OII Europe, which was founded during the Second International Intersex Forum in Stockholm, Sweden on Human Rights Day 2012 (December 10) as a network of national European intersex-led organisations. After our official founding as a charitable non-profit organisation in 2015, I served as part of the executive board for several years. I have been a member of the staff since January 2019, working as the Awareness Raising & Campaigns Officer, where I can integrate both my activist and artistic backgrounds.

### **What are the goals of OII Europe in the short and mid-term?**

Our main goals are based on the Malta Declaration, formulated at the 3rd International Intersex Forum 2013. We work for the full implementation of human rights, bodily integrity and self-determination for intersex people, and the main short-term goal would be the legal prohibition of non-consensual medical and psychological treatment.

Something we already work on, but which could be considered ongoing or a mid-term goal, is the promotion of self-awareness, visibility and recognition of intersex people and for the full protection against discrimination and the adoption of "sex characteristics" as a protective ground.

In general we are working on supporting and informing stakeholders, multipliers, allies and educating the society at large on intersex issues from a human rights perspective.