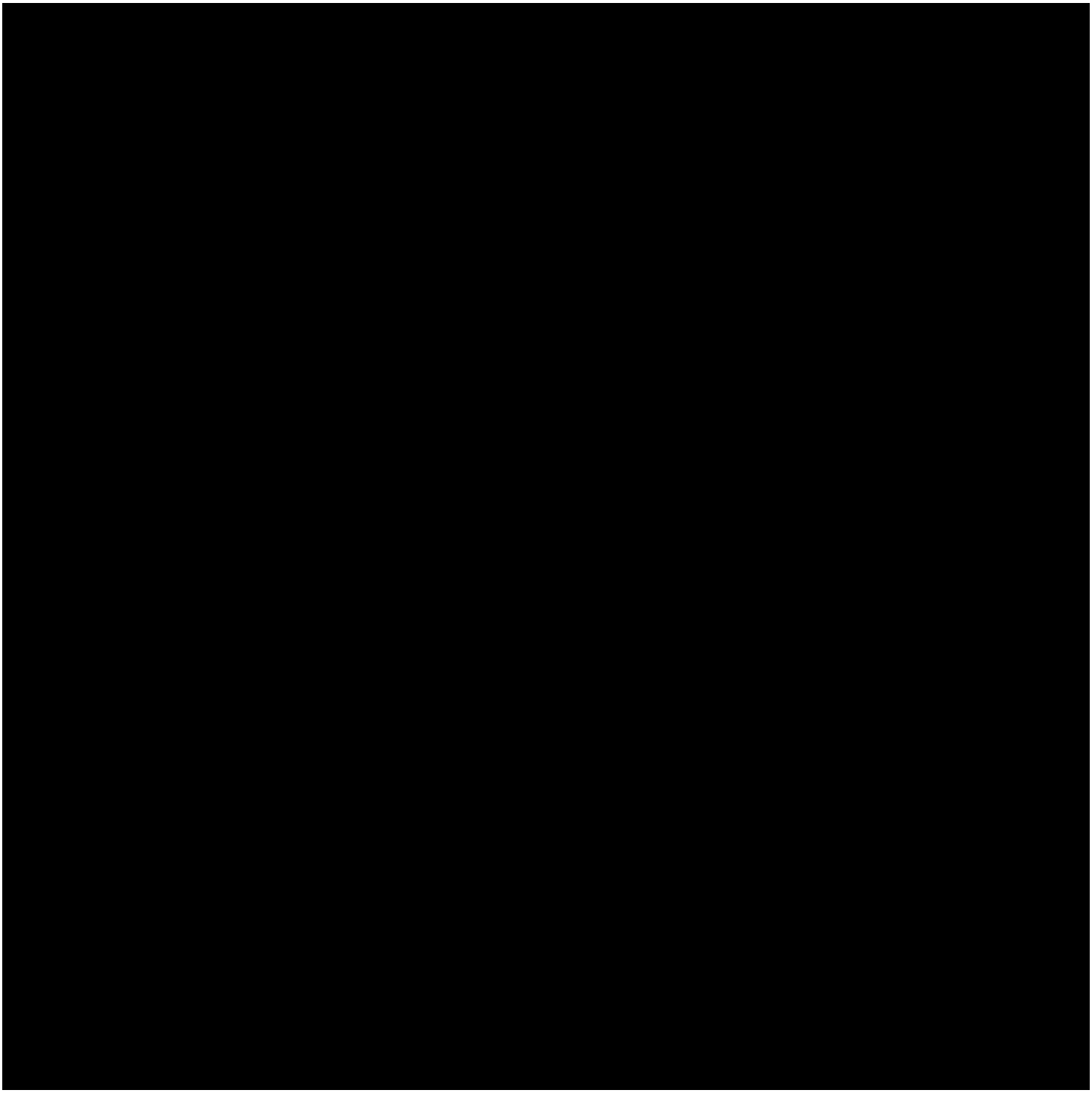
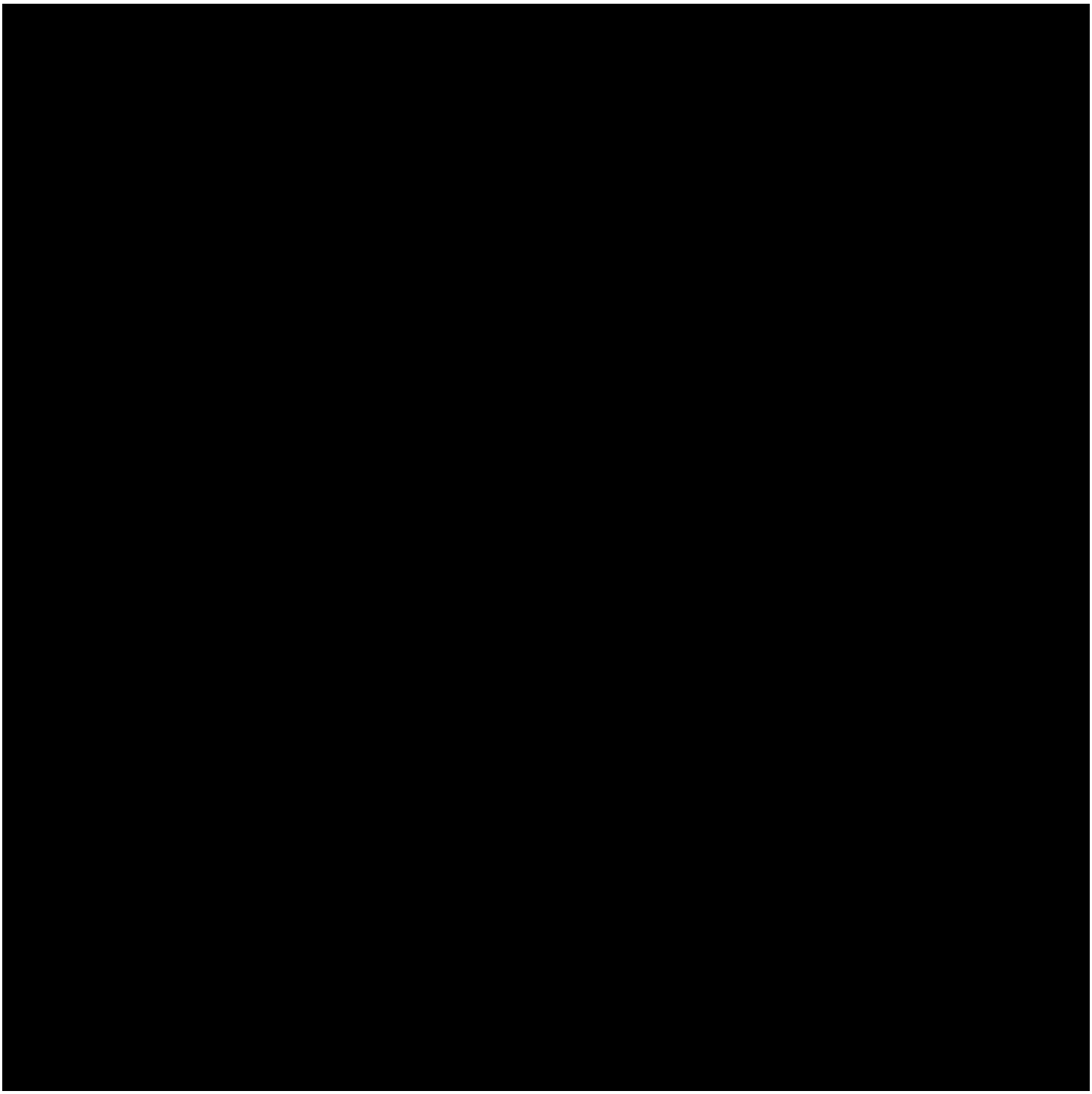
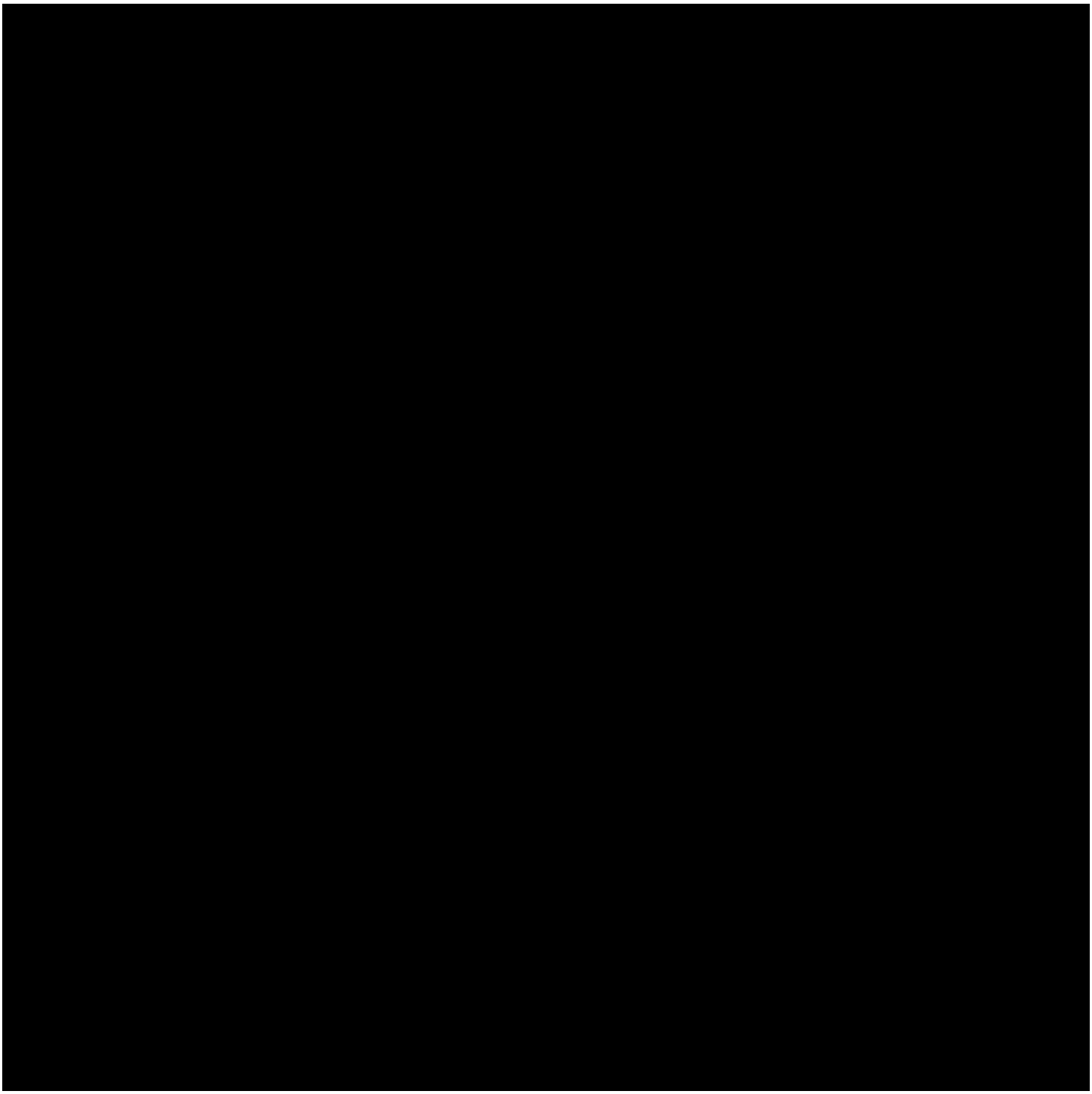
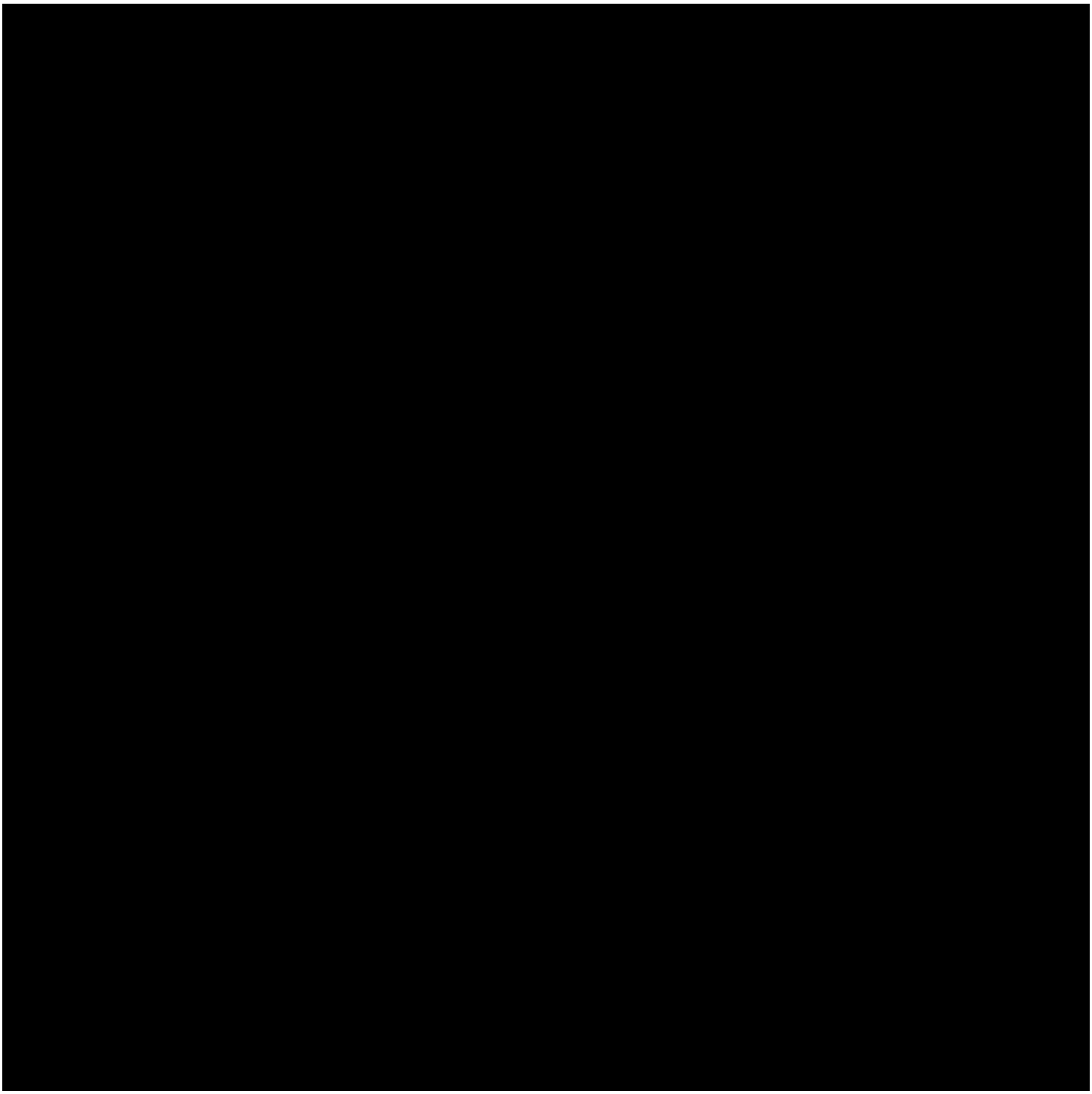
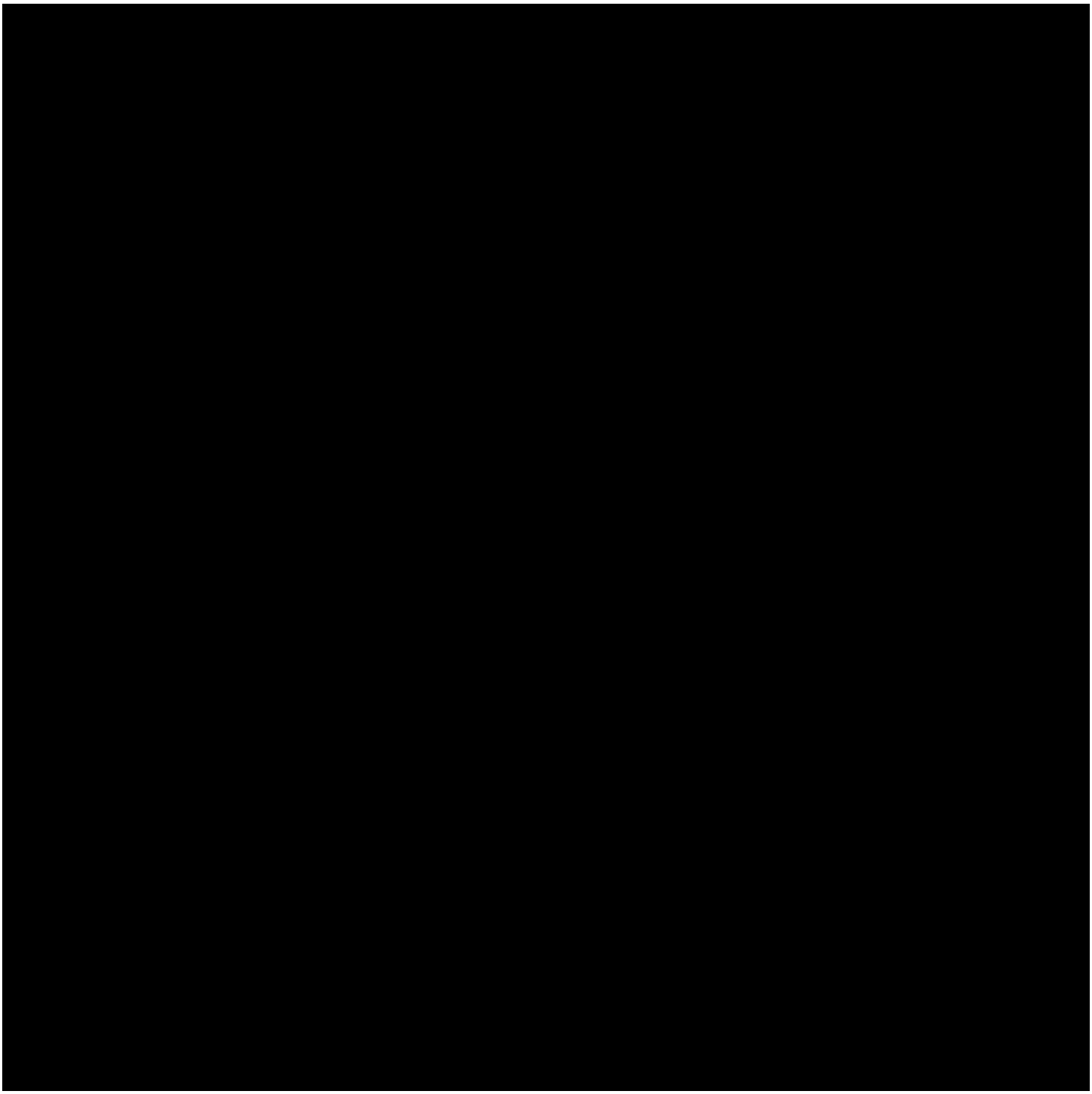
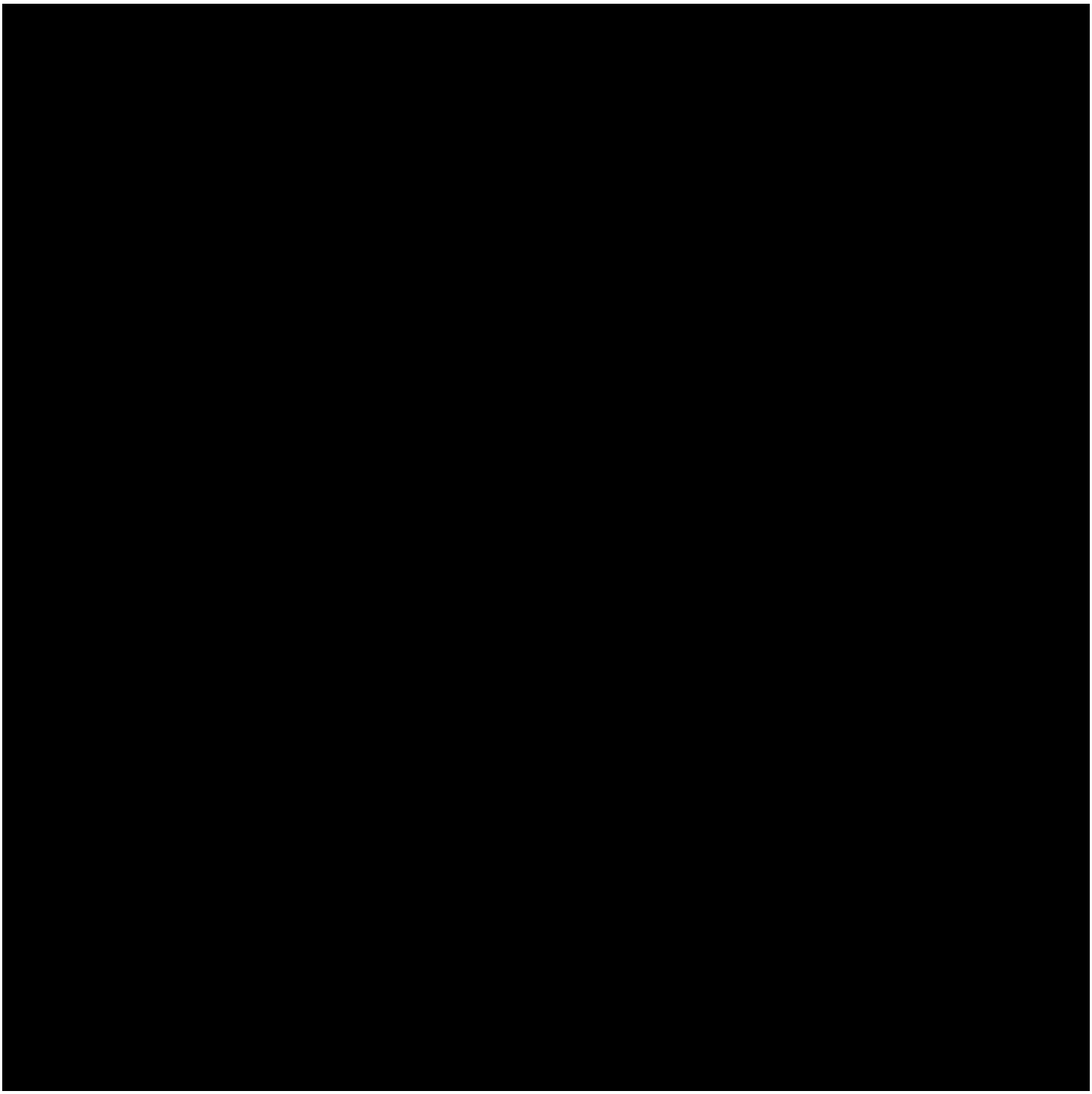


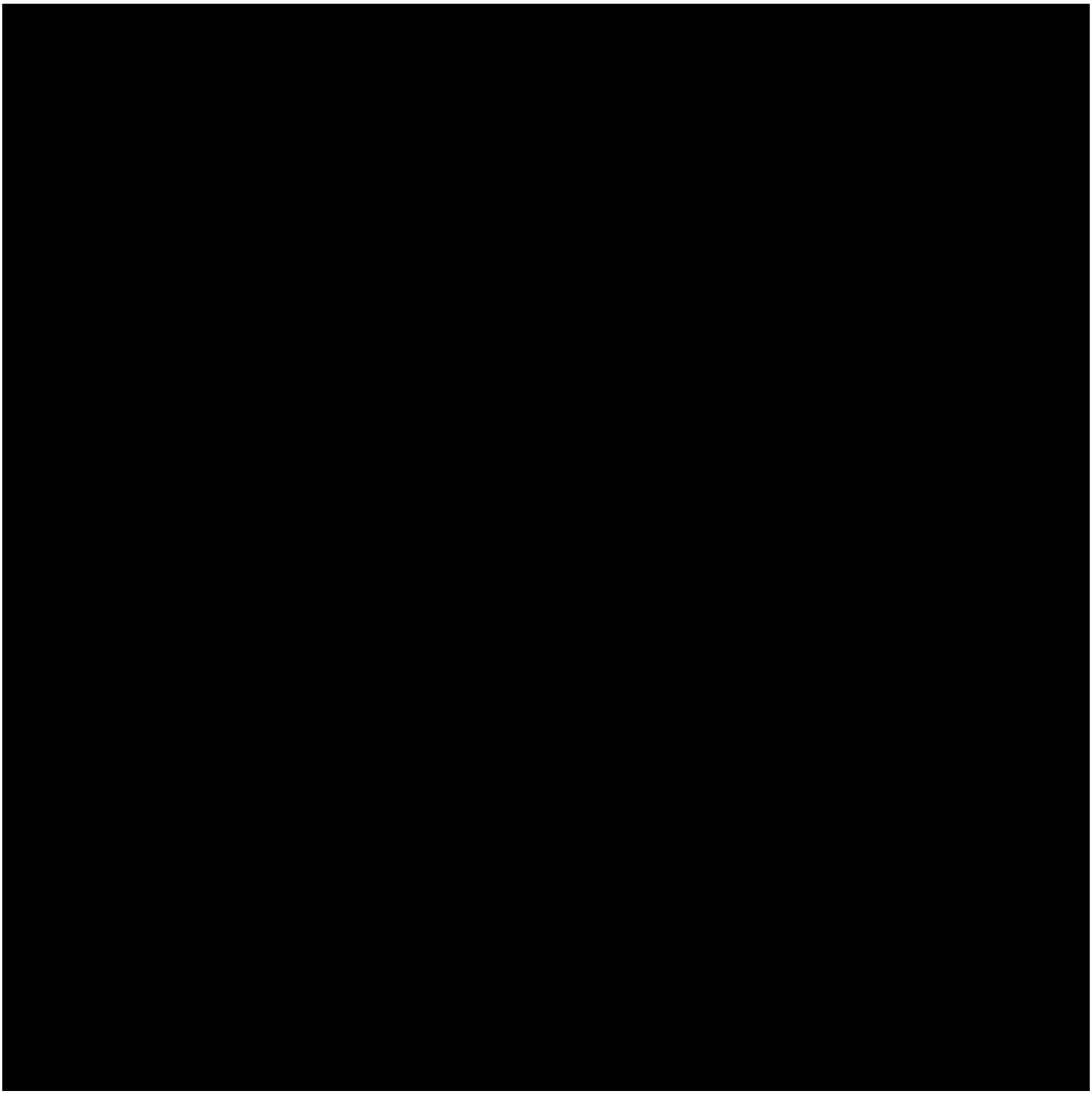


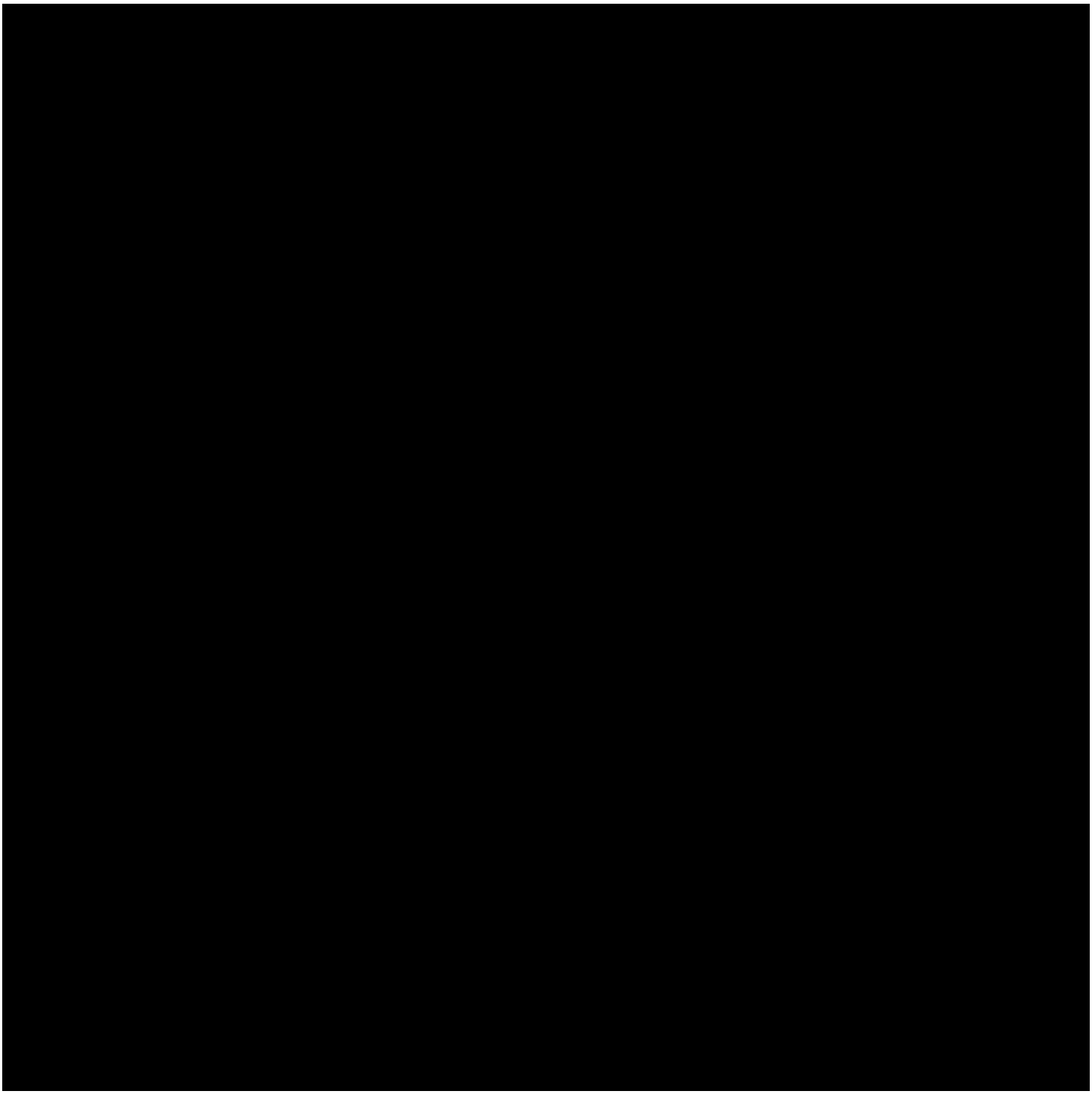


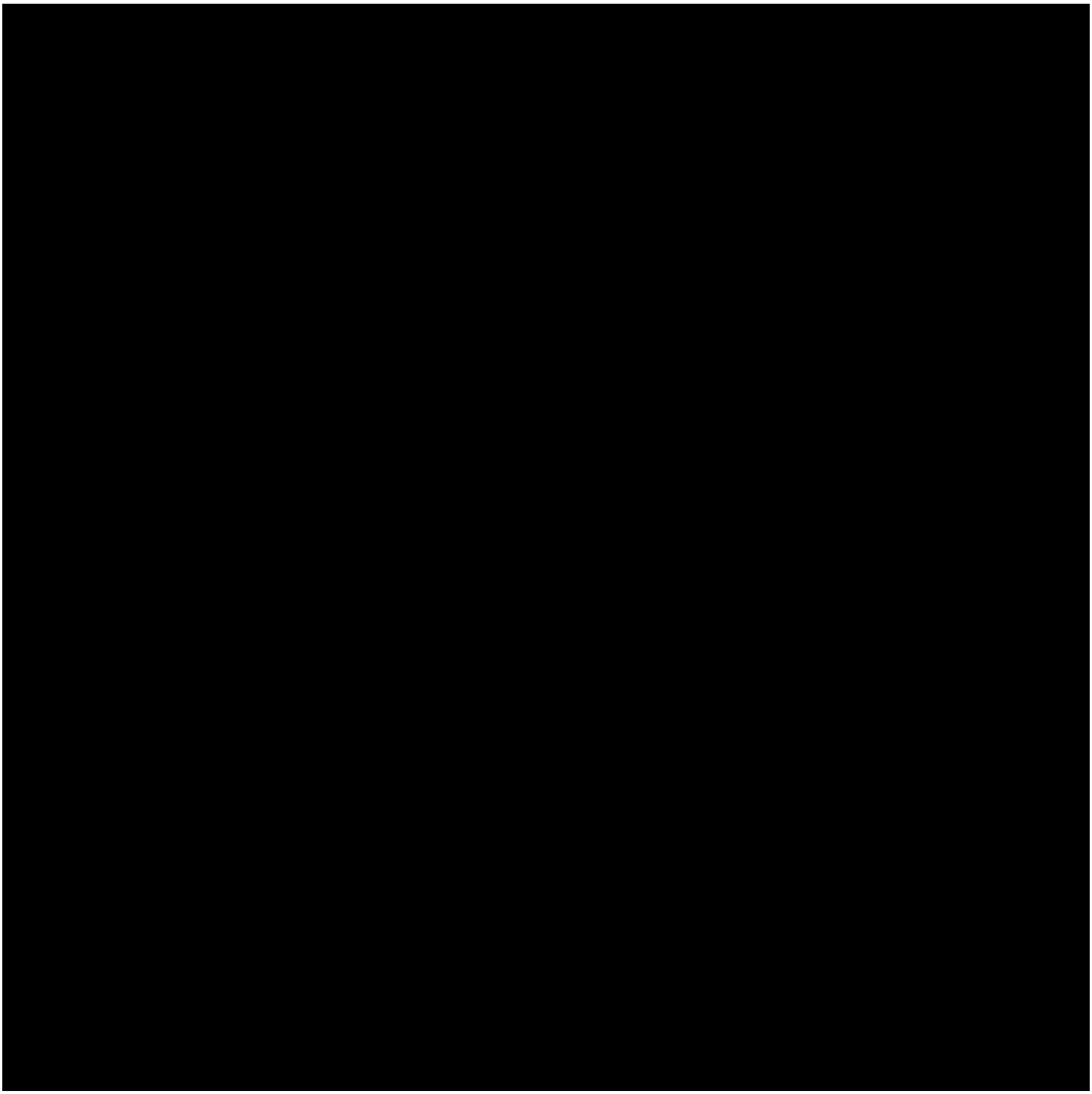












Series Six Degrees of Separation
Six Degrees of Separation
Series
Organized by The Editors
What makes sense to publish in these times? We wanted to avoid “this is the new reality” hot takes responding to the COVID-19 pandemic. And but also… there *is* this new reality to contend with (layered on all those old realities, of course).

How are artists and writers in the Bay Area doing that contending? Here are a few local perspectives — including our own contribution, a resources page we compiled last month, with help from SFMOMA colleagues and Open Space community members.

May 18, 2020

There Is No One Way

by Alice Wong

Book event at the San Francisco Public Library. In the foreground is a row of people sitting in chairs. In the background is a row of panelists sitting at tables with microphones, and a screen showing the transcription of the event in real time.

> "In a time of destruction, create something…"
>
> — Maxine Hong Kingston

Living during the coronavirus pandemic means living in separation and intimacy simultaneously. Isolation can happen deep inside you or result from the built and social environment. Connection and being loved by others can happen without touch, words, or sound. Staying at home and being socially distant is not new to disabled, older, sick, immunocompromised, and housebound people like myself. Many of us maintain rich and fulfilling networks in a world designed to exclude and devalue us. This pandemic is just one of a series of crises we have survived.

As with many other marginalized communities, disabled artists and activists have always figured out how to exist and thrive in ways that may seem atypical or inferior by "normal" standards. I have incredible relationships with friends and colleagues whom I haven't met face-to-face for years — in part because I've worked with fellow activists and writers to build online

communities where we can find one another and mobilize collectively. In 2016, I collaborated with Gregg Beratan and Andrew Pulrang in #CripTheVote, a nonpartisan online movement encouraging the political participation of disabled people that has since become a network for discussion about disability issues. Several years ago, after novelist Nicola Griffith tweeted the hashtag #CripLit, we worked with her to host a series of Twitter chats for disabled writers, focusing on publishing, representation, disabled narratives, and storytelling.

Disabled writers and artists have long railed against the difficulties in applying for and then requesting access at residencies, internships, conferences, and events. This does not even include the barriers disabled writers face in having their work considered for publication. Imagine my ambivalence over the last two months: suddenly concerts and performances are livestreamed, video conferencing is the default mode of working and meeting, and the concepts of time and productivity have become more flexible as people collectively freak out and struggle to adjust. It's a bittersweet time, to say the least.

Photo of Maysoon Zayid, a Palestinian American woman with long black hair swept to one side, wearing a print top and black leggings, with Alice Wong, an Asian American woman in a wheelchair with a silver sequined top and a mask over her nose attached to a tube. Behind them is a white backdrop with the DREDF logo.

I moved to San Francisco from Indianapolis more than twenty years ago and never looked back. The rich history of disability rights and culture in the Bay Area called, welcoming me with open arms. The first time I went to Caffe Strada in Berkeley, I was amazed to see disabled people all around me — and more importantly, this felt natural. They belonged there as much as anyone else. There's nothing more joyful than being in a room filled with disabled people, laughing, gossiping, scheming, and celebrating. And these gatherings happen all over the Bay Area; there is always something going on, like Superfest, an

annual film festival organized by the Paul K. Longmore Institute on Disability at San Francisco State University, and the two major events I attended last fall and winter: a fundraiser for a disability rights organization in Berkeley and a book panel of all disabled writers at the San Francisco Public Library. I am so grateful for these experiences and know there will be similar online and in-person events in the future.

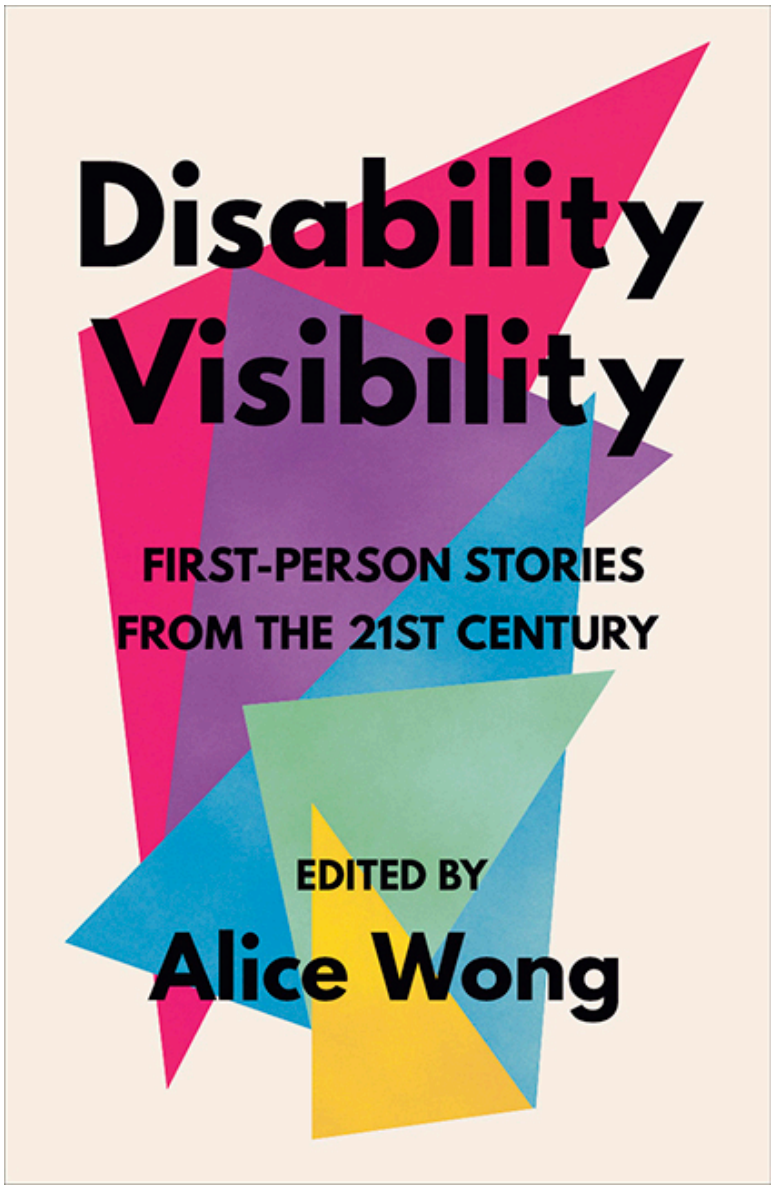
Photo of a large atrium filled with tables and people. In the foreground on the left is Alana Theriault, a white disabled woman in a wheelchair wearing a white shirt, tie, and black sneakers, talking with Alice Wong, an Asian American woman in a wheelchair wearing a silver sequined top and a mask over her nose attached to a tube.

Having progressive neuromuscular disability means I am considerably weaker than I was five to ten years ago — but I've never felt more engaged and alive than I do now. Is it the virus? Is it the hand sanitizer slathered over my bony fingers and hands? What is clear to me, based on experience and past mistakes, is that I know what I want to do with my time and capacity. I wield both like swords, cutting out the shit and carving into the good meaty bits I seek as a creator, shaping them into something new and beautiful.

The urgency of this time elicits an impulse in me to tell my own story and amplify the stories of disabled people — to create in the face of overwhelming pain, bigotry, and oppression. I guffaw thinking about how often ventilators, an essential part of my cyborg body, have been in the news of late. The political and cultural circumstances of this historic time led me to write about my experiences as a disabled vent user and the eugenic implications of healthcare rationing and shortages that are happening across the world. With my podcast, Disability Visibility, I produced a series of episodes about the impact of COVID-19 on disabled people, in particular disabled people of color, who are disproportionately at risk. On my blog, I

published guest essays by disabled and immunocompromised people examining fatphobia, ableism, and genocide. All of these activities were unplanned, created in response to the overwhelming fear, sadness, and anxiety I feel in this moment.

Artists are essential cultural workers. We need media, and stories of this time to expose the hypocrisy and flaws, provoke discomfort and reflection, advance our understanding of the human condition, provide sustenance to our spirits, and agitate for a better future. At the beginning of 2020 I imagined I would be focusing on the launch of my book and activist work around the presidential election. With everything in flux and uncertain (something disabled people are familiar with), I am pivoting to maximize access and impact. I want to leverage everything I have to support and bring attention to the communities I'm part of, just as many Bay Area artists and activists are doing right now.



In the middle is an image of a book titled *Disability Visibility: First-Person Stories from the 21st Century*, edited by Alice Wong. The book cover has overlapping triangles in a variety of bright colors with black text overlaying them and an off-white background. Book cover by Madeline Partner.

I worried several months ago about how I would promote my upcoming book, *Disability Visibility: First-Person Stories from the Twenty-First Century*, because I do not travel and have limited stamina. Writer, poet, performer, cultural worker Leah Lakshmi Piepzna-Smarasinha wrote in *Guts Magazine* about the toll book promotion and tours take and how she and other disabled, neurodivergent, and chronically ill writers adapt and bend normative capitalist expectations: "…if there's one thing disabled people are good at, it's saying *there is no one way it has to be*." This idea, along with other disabled wisdom, is something everyone can learn from.

My one "traditional" book event was going to be at the San Francisco Public Library this July, timed to mark the thirtieth anniversary of the Americans with Disabilities Act. I imagined signing books, giving a reading in front of my family and friends, and getting a chance to thank everyone for supporting me. I decided to cancel it: even if the shelter-in-place order expires after May, I do not anticipate that I will feel safe. Instead, I've organized a series of online book events this summer and fall featuring myself and some of the contributors to the anthology.

As I said when announcing the call for submissions, being published is a privilege — and yet pressures to promote our work can be extremely arduous for disabled writers, as we may face inaccessible buildings, difficulty traveling, or other barriers. COVID-19 has only exacerbated these evergreen conditions, as writers with books coming out this year or next have had their launches delayed and book tours cancelled. The Disability Visibility Book Circle is my way of responding to the pandemic and helping my peers: the project offers one-time grants of $1000 to fifteen writers in the US who have been or will be published from January 1, 2020 through June 30, 2021. The money will allow authors to organize their own online events, free and open to the public, with their videos archived on YouTube and my website. I cannot wait to announce the recipients this summer and get money to them.

There's a tremendous amount of mutual aid and community organizing happening, and this is my contribution, since I can't sew face masks or provide direct aid to neighbors in need. Utilizing my resources and platform, I hope the Disability Visibility Book Circle will support the work of disabled authors and model the kind of accessibility we should have for *all* events — now and in the future. Creation, in the face of destruction and death, can come in big and small forms. We should welcome all of it.

Tags: Alice Wong, Disability Visibility, Six Degrees of Separation

Comments (3)

- *Wayne* says:
  February 9, 2023 at 4:44 am

  It has been a rough few years. However, the world is slowly but surely conquering the Coronavirus epidemic. I believe in us!

- *nonny* says:
  January 21, 2021 at 1:20 am

  the coronavirus is a fight that we all must unite to conquer. there are diverse process as seen all over the world that must be used to combat it. some stories have been shared lately on successful treatments. the virus is beatable

- *Megan Metcalf* says:
  May 31, 2020 at 10:44 pm

  THIS. So much THIS. Thank you for providing this perspective on the pandemic and for all the work you are doing, now and otherwise.

Leave a comment

Please tell us what you think. We really love conversation, and we're happy to entertain dissenting opinions. Just no name-calling, personal attacks, slurs, threats, spam, and the like, please. Those ones we reserve the right to remove.

Leave a comment

Name
Required
Email
Required, will not be published
Website

Save my name, email, and website in this browser for the next time I comment.

Publish

Search

- Magazine
- Categories
- Archive
- Collaborators
- About

- Open Space is SFMOMA's online & live interdisciplinary commissioning platform.

San Francisco Museum of Modern Art

San Francisco Museum of Modern Art
SFMOMA's Open Space is a home for unruly, non-instrumentalized gestures. We're anchored in the Bay Area but we cast a wide net, commissioning and supporting critical + experimental + poetic ruminations by artists, writers, and thinkers from all over the world. We also host parties, performances, and other live events. Learn More
RSS
W.A.G.E.
Certified
Join The Newsletter

- Terms of Use
- Privacy Policy
- Login

W.A.G.E. Certified Institution

×

Sign Up

Join our newsletter for infrequent updates on new posts and Open Space events.

Email *

Required, will not be published

Submit