

TODAY: Last chance to see "The Cure" exhibition by Megan Euker



International Museum of Surgical Science
A Division of the International College of Surgeons



LAST DAY: **see "The Cure" by artist Megan Euker**



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Closing July 1

For the past three years, Megan Euker has devoted her research and artistic practice to orphan disease (OD) advocacy, specifically focusing on the cure of Sickle Cell Disease and Beta Thalassemia through gene therapy. Called 'orphan diseases,' these conditions affect small patient populations who have been 'orphaned' by the pharmaceutical industry in pursuit of more lucrative opportunities. Certain incentives have helped remedy this oversight, but all too often lead to monopolies on new medications and high prices for those most in need. In the midst of this is a battle: the ongoing court cases of Errant Gene Therapeutics (Chicago) versus Memorial Sloan Kettering Cancer Center and Bluebird Bio (New York)* and Errant Gene Therapeutics versus Nick Leschly and Third Rock Ventures (Boston).

The exhibition places these legal cases at the heart of an investigation into orphan diseases and the role of the pharmaceutical industry in controlling treatment research and patient access. Music and videos of the Orphan Dream Band, a group founded around orphan diseases, will fill the space with rock, blues and soul pieces about life with these afflictions.

Euker makes use of illustrations and diagrams explaining gene therapy, Sickle Cell Disease, and Beta Thalassemia; documents and articles relating to court cases; and other data sets to present a case of corruption and fault in the world of "Big Pharma." She reflects on this data and research through her artmaking, 3D printed and cast metal sculptures, timelines, data visualization, and book promotion to encourage the viewer to both contemplate the workings of the industry and strive for hopefulness and change for those most affected by its practices.**

**New York State Court e-track index number 150856/2017*

***All graphics produced in collaboration with TJ Fulfer; music and videos by The Orphan Dream Band*

In the News:

["How Art Reflects the Changing History of Medicine," ArtandObject.com, June 6, 2020](#)

["Pharma Drama: bluebird bio, Inc. Directors Accused of "Grossly Excessive" Compensation While separate Errant Gene Therapeutics Lawsuit Heads for Trial" TrialSiteNews.com, April 3, 2020](#)

About Megan Euker:

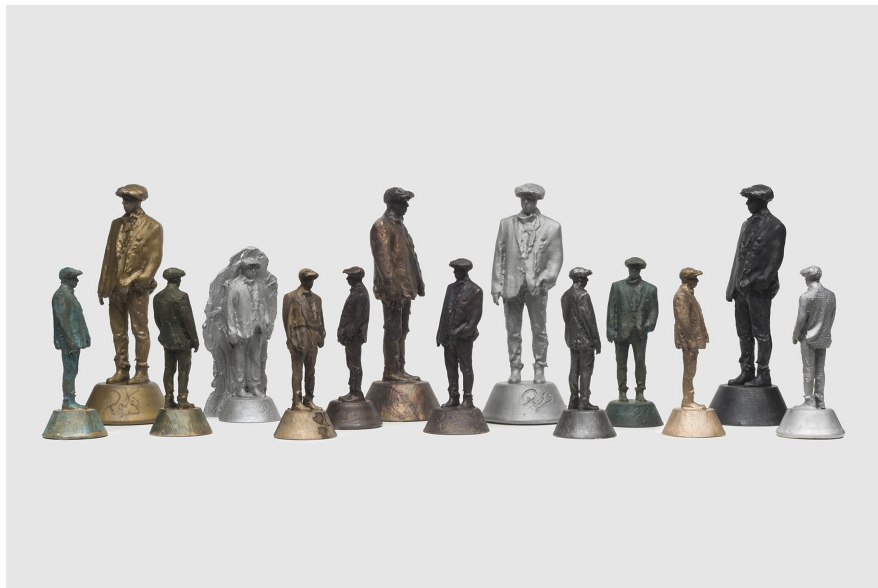
Megan Euker has been represented by Linda Warren Projects in Chicago since 2008 and featured in The International Museum of Surgical Science; Matthew Rachman Gallery, Chicago; The University Club of Chicago; Chautauqua School of Art, New York; Prince Street Gallery, New York; The Storefront Project, New York; Togonon Gallery, San Francisco; College of DuPage, Illinois; Beverly Arts Center, Chicago; and Western Exhibitions, Chicago and other prestigious venues.

In 2017, at Casa Cava in Matera, Italy, a world heritage site, she, along with The Orphan Dream Band, presented the first Orphan Dream Award to Dr. Franco Locatelli. Her sculptures have appeared on Italian television including Canale 2 and TRM24. She presented the second and third Orphan Dream Awards to Dr. Michel Sadelain of Memorial Sloan Kettering Cancer Center and Dr. John Tisdale of the National Institute of Health. Megan is an orphan disease advocate and is dedicated to supporting the mission of Errant Gene Therapeutics.

She has been the recipient of such honors as a Fulbright Fellowship to Italy; two Faculty Enrichment Grants from the School of the Art Institute of Chicago; a Compassion and Belonging Grant from SAIC; the Artists' Fellowship, Inc. Grant; Change, Inc. Grant; Artist Assistance Grant; two CAAP (Community Arts Assistance Program) and two DCASE grants. Euker received her BFA and MFA from the School of the Art Institute of Chicago.

Euker is a Lecturer in the departments of Architecture, Interior Architecture and Designed Objects; Contemporary Practices; and Continuing Studies at the School of the Art Institute of Chicago.

MeganEuker.com



Eleven Patrizio Sculptures, Cast and Patinated Bronze and Aluminum, Maple and Steel table, 2020

About TJ Fulfer:

TJ Fulfer is a designer, collaborator, visual storyteller, photographer, musician, and founder of APOTH Creative (Lombard, IL). With over 15 years of experience, TJ strives for innovation, collaboration, and clarity in an ever-changing creative landscape. Fulfer received his BFA in Graphic Design at Columbia College Chicago. Beyond the visual world, TJ makes a variety of music alongside his life partner, Meagan Zahora, and his close friends.



Orphan Dream Band wall (I want you to stop pimping the middle class): Installation at The International Museum of Surgical Science (4257), music videos, vinyl lettering, cd and case, 2020

Background: Megan Euker and Orphan Disease Advocacy:

In December of 2016, Patrizio approached me in a Café. He's a former Chicagoan, now resident of Italy; former trader, now singer/songwriter; father of three and founder of a gene therapy firm searching for the cure of Sickle Cell Disease and Thalassemia, a rare inherited blood disease.

Patrizio and I spoke in Italian about the many facets of his work as an advocate for orphan diseases. Intrigued, I began a frantic investigation into the incredible world linked to his efforts, his son's illness and orphan diseases. I raced through a New York Times story written about his endeavors and listened to "One More Day," a song from his third album,

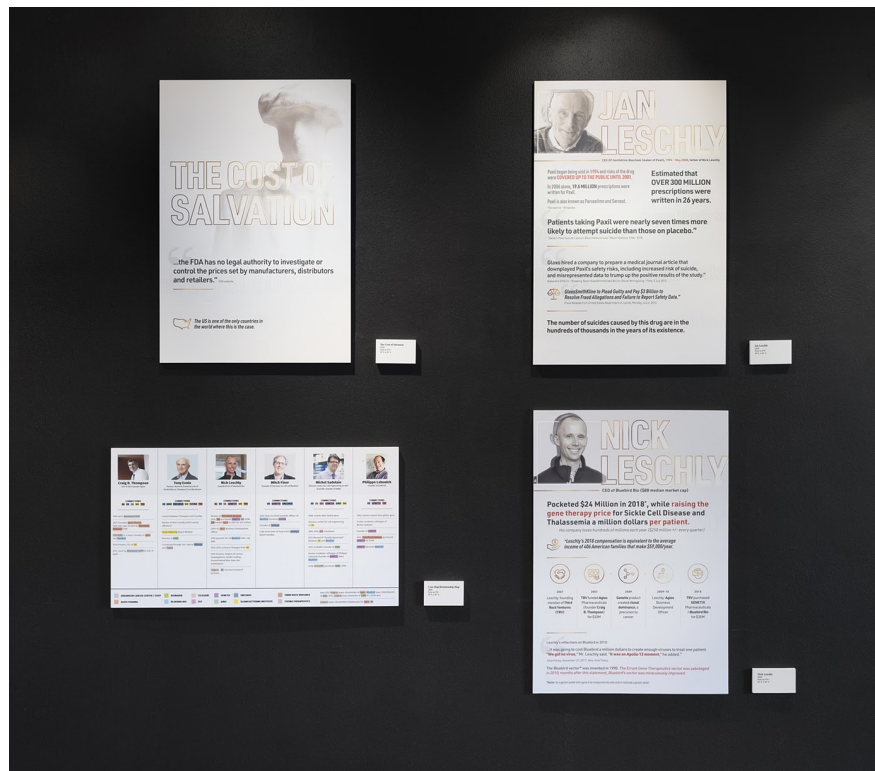
Orphan's Hope. I discovered the beautiful vulnerability of a parent, asking for more time. I decided to participate in the orphan disease (OD) struggle the best way I could—with my art.

Patrizio was scheduled to perform in a music concert in Italy wearing a Versace jacket, gifted by parents who lost two children to Batten's, a rare and degenerative neurological disease.

He couldn't wait to perform in that jacket in January 2017, hoping to take and send a photo to the family in honor of the child. Unexpected snow in the south of Italy caused the concert to be canceled. I asked him to bring the jacket back to the U.S. so I could take 3-dimensional "photos" of him and cast a bronze sculpture to give to the family.

The gifted statue was featured in a CBS news segment about the VanHoutan family struggle. Shortly after people began to ask for statues; some suggesting the cast metal sculptures be presented as awards for people making a difference in orphan disease research. The statues embody the story of the jacket and the stories surrounding Patrizio's research. The first Orphan Dream Award was presented at the Orphan's Dream concert "La Notte delle Malattie Rare/ORPHAN'S NIGHT" at Casa Cava, Matera, Italy, in December 2017 to Dr. Locatelli of Bambino Gesù Hospital in Rome. The second and third awards were presented to Dr. Michel Sadelain of Memorial Sloan Kettering Hospital and Dr. John Tisdale of the National Institute of Health.

In Patrizio's words, "This is the parent of a child with OD. Nothing in life fits. He's a foreigner in every land, wearing his jacket like a military uniform, his rank on his hat and forever seeking the Cure."



The Cost of Salvation: Installation at The International Museum of Surgical Science (4237), Prints on PVC, each 24" x 36", 2020