

LEGACY SPECIAL REPORTS

# Family ties: How ordinary people influence autism research

BY SPECTRUM

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Researchers and families in the autism world have forged a special relationship. From the beginning, it was often parents who urged scientists to investigate this misunderstood and neglected condition. In the best cases, the two groups have worked side by side, forming deep connections based on mutual trust. But sometimes, their priorities and methods are diametrically opposed.

In this series, we tell four stories about the connections and conflicts between scientists and parents in this unique community.

On 14 September, you'll meet **Karlee and Leslie**, two parents who began experimenting with giving their children marijuana compounds after nothing else worked. You'll also hear from the frustrated scientists who are eager to study the drug but are hamstrung by federal regulations.

On 21 September, we will introduce you to **Ariane**, who tried nearly every alternative therapy marketed to parents of children with autism — until she stopped searching.

On 28 September, we'll tell the story of the families who are launching their own **single-person clinical trials**, and their efforts to transform their findings into solid science.

On 5 October, the series wraps up with a portrait of a world-class autism research institute, and the **families who shaped its agenda**.

In addition, this *Spectrum* podcast delves in to the sometimes-complicated, sometimes-complementary relationship between the autism community and researchers. The podcast features the voices of parents and scientists spotlighted in the series. Ariane Zurcher, the mother of a young woman with autism featured in "The seekers," talks about why she sought unproven treatments for her daughter, and why meeting adults on the spectrum dramatically changed her perspective.

David Amaral, research director of the University of California, Davis MIND Institute, describes how the institute's researchers balance the founding families' priorities and their own scientific pursuits. We also take you behind the scenes with the journalists as they talk about their experiences with these stories.

To listen, click 'play' below.

<https://www.spectrumnews.org/wp-content/uploads/2016/09/Spectrum-Sept16-Podcast.mp3>