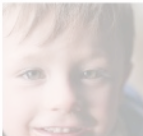
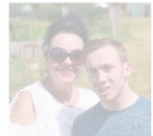


FASD AWARENESS CHARITY IMPACT REPORT 2024

**SUPPORTING
THE FASD
COMMUNITY**



FASD AWARENESS
FOETAL ALCOHOL SPECTRUM DISORDERS



produced by **ANDREW KEEPING** (CEO FASD Awareness)

SUPPORTING THE FASD COMMUNITY

FASD Awareness was established in 2018 to support the FASD community and raise awareness of Foetal Alcohol Spectrum Disorders (FASD).

These two aims are met by providing support & friendship groups, activity days, education, training, and information to the FASD community and the wider population.

FASD Awareness is a family-focused organisation and is the essential bridge linking those with lived experience with clinicians and support services.





ANDREW KEEPING
CHIEF EXECUTIVE

When **Tracy Allen** (Founder) approached me in 2017 to help her in starting a charity to support local families in the south east of England struggling with accessing services and advice in Foetal Alcohol Spectrum Disorders (FASD), we could not have dreamed that in 2024 **FASD Awareness** would be one of the world's leading charities in the FASD Community.

This is no fluke, however, as the need and desire are there for all to see. We also have a passionate, caring and dedicated team working tirelessly to make an impact. We are driven by the generous feedback we receive, and will strive to continue increasing awareness, improving services and offering the much-needed support of all individuals and families living alongside FASD.



PEGGY MURPHY
CHAIR OF BOARD OF
TRUSTEES

At **FASD Awareness**, we are dedicated to putting those individuals and families living with FASD at the centre of what we do. We encourage feedback to our experienced and qualified board of trustees and listen to the needs of those with the lived experience. We ensure our message is clear and delivered in the most appropriate manner. Through our governance and strategic planning we are making sure that FASD Awareness, Andrew and Tracy can continue to provide support and education to the FASD community, all relevant sectors and the wider population for years to come.



TRACY ALLEN
FOUNDER

In 2016, my mission was to raise funds to support the awareness of Foetal Alcohol Spectrum Disorders (FASD) and serve the FASD community.

And so, the **#BeAware** campaign was born from our lived experience. The realisation of having a FASD informed network wrapping around us and professionals that truly identified and understood FASD was imperative.

Our **FASD Awareness** charity is now a dream come true. It is such a privilege to support the amazing FASD community. The art of listening from those with lived experience has helped us develop a charity using their voice to forge future FASD pathways.

EVALUATION & FEEDBACK

At FASD Awareness, we prioritize amplifying the voices of the FASD community. We accomplish this through evaluation forms, feedback, and surveys that help us understand what our community finds valuable and what they need. We actively invite suggestions from everyone who interacts with us, allowing FASD Awareness to develop meaningful and pertinent resources, events, and workshops aimed at educating, supporting, and improving lives while fostering a deeper understanding of Foetal Alcohol Spectrum Disorders. The positive feedback and heartfelt gratitude we receive following our FASD Awareness presentations, support groups, events, and webinars motivate us to continue our mission for positive change within the FASD landscape.

Here is a cross-spectrum of some of the feedback we receive at FASD Awareness.

QUOTES & ARTICLES

“You got the Kent FASD service going. You (Andrew Keeping) and Tracy (Allen) and your FASD Awareness group. You banged on at the commissioners there and didn’t let it go. That’s how you’ve got to service it. I didn’t do it. You did it!”

Prof Raja Mukherjee (International expert in FASD)

on the development of the first Hub and Spoke Diagnostic model in the UK
(March 2024 Webinar #23)

“How lucky were we, that day, to find the charity FASD Awareness. As we were feeling isolated due to covid and the realisation that FASD was about to consume us... This charity has opened its arms to not only us as parents but to our Sons and created not only a wealth of knowledge but coping strategies, ideas , other ways to tackle issues we face and crucially that peer to peer support in their monthly meetings online.” **Julie**

“One of Andrew Keeping’s most impactful endeavors revolves around his ardent advocacy for FASD awareness. As the Chief Executive at FASD Awareness, he stands as a beacon in the quest to prevent FASD and improve the lives of those affected. His initiatives span educational campaigns, collaborations, and the establishment of crucial support structures...Andrew spearheaded various initiatives under FASD Awareness, employing innovative strategies to increase understanding and support for FASD. The #BeAware campaign, a series of educational films and case studies, became a pivotal tool in educating the public about the science behind FASD and the real-life experiences of individuals affected by it.”

LA Weekly Magazine Jan 2024

SUPPORT GROUPS AND 1-2-1'S

While we have seen an increase in participation in our Parent/Carers support groups, one-to-one sessions, the FASD Adults Friendship Group, and the Junior FASD Friendship Group, we recognize the importance of expanding these offerings. We aim to introduce additional sessions throughout the month and provide alternative days and times to



ensure more individuals can participate without overcrowding existing groups. We have also identified the need for more focus groups like a “Guy’s Group” for male carers, a “Siblings Group” and a “Mentoring Scheme”. We have also found the need to develop our “Yoga” and “Sensory Circuits” sessions, which have proved so valuable.

“It is the only place that I can go and people are just like me. We can have a laugh without judgement. I have friends here that just get me.”

Steph (Adult FASD Friendship Group)

“I cant wait for the Friendship Group each month. We have built great bonds and Maggie May is just brilliant! She’s the same as us and I can trust her advice.”

Chloe (Junior FASD Friendship Group)

The FASD Collation and Baseline tools, developed by Tracy Allen (alongside some partnering organisations), and used during one-to-one sessions with caregivers, play a crucial role in identifying each individual's unique strengths and weaknesses. These tools provide GPs and other professionals with a deeper understanding of the

“During this past two months we have struggled and were at crisis point. FASD is so very misunderstood and compared to Autism and ADHD which is a dangerous concept as they are very different despite their overlapping traits at times. Did we go to Post Adoption, Social Workers, Adult inclusion. None of these people understood our challenges, none understood the concept of FASD and the 428 co morbidities that can present. But one place did and that was the charity FASD Awareness. They instantly offered a one to one online meeting. Tracy listened, empathised and made us feel that what we were experiencing was typical things that most FASD families will experience sadly at sometime. This gave us one crucial thing and that was hope. We are still in this situation now and still in crisis as a family but I do believe that I would have had a mental breakdown support and listening ear of Tracy and this FASD Awareness Charity.”

individual, facilitating accurate diagnoses and comprehensive management and support plans. Professionals have reported that these tools are invaluable for delivering precise and relevant information to assist individuals with FASD and their support networks. As a result, there are fewer incomplete diagnoses, leading to more positive outcomes and brighter futures for those impacted.

FAMILY ACTIVITY DAYS

The impact of our Activity Days has been invaluable over the past five years. Many participants return repeatedly to spend time with their newfound friends. Feedback

consistently highlights their appreciation for the opportunity to share experiences and learn from others who have faced similar challenges. They feel a strong connection to like-minded individuals and consider the charity their FASD family. Many who initially



attended our Activity Days in crisis have since developed FASD Management Plans that support both them and their support networks. These individuals now return to offer advice and support to new families and caregivers who are struggling. This has fostered trust and empathy within the FASD community we serve. At FASD Awareness, our priority is to support the FASD community by ensuring their voices are heard and designing our services based on their suggestions, ultimately facilitating positive outcomes for all.

FASD AWARENESS SUPPORT WORKERS

The support work team serves as the foundation for all our activities, outings, and events, ensuring that everyone enjoys a progressive and fun experience. With training in effective techniques and lived experiences across a spectrum of neurodiversity, our dedicated team members are committed to helping and doing everything possible to ensure a safe and enjoyable environment for all participants.

Easily identifiable in their orange branded shirts, each support worker brings a wealth of knowledge and experience, ready to assist, listen, and engage in conversation about anything. Whether it's playing a game or simply providing a non-judgmental presence, they are dedicated to making everyone feel comfortable and supported.



MONTHLY WEBINAR SERIES

Our acclaimed and popular monthly webinars (uploaded to YouTube) are shared worldwide by leading FASD and Neurodiversity organizations in Canada, Spain, the Netherlands, the USA, Australia, New Zealand etc.

**“Thank you for such a strength based and anti oppressive webinar.”
E. Smith**



**“I have had a watch of your webinars and thought they were so beautifully presented, low key, no hype and really informative. Just great! Well done you.”
J. Birth Mother**

“Outstanding!” “10/10!” “Simply brilliant evening.” “Fantastic.”

“Amazing, informative and easy to understand such complexity.”

“Very informative, learned loads. Good pace, so much more engaging than a lecture.”

“Great frank discussion. I have been on a few courses but learned more in this hour.”

“Great respect for giving a voice to those with FASD. Give me more”

“Brilliant. Always such great guests that Andrew immediately puts at ease and gets to the guts of the issues.”

TRAINING WEBINARS AND PRESENTATIONS

The recent launch of the *FASD Health Needs Assessment* and *FASD NICE Quality Standards* in the UK has highlighted the need for a deeper understanding of Foetal Alcohol Spectrum Disorders, including their causes and societal impacts. Awareness of FASD is increasing among community paediatricians, midwives, SENCOs, GPs, social workers, lawyers, police officers, foster carers, and adoptive families. There is a pressing demand for clear and accessible information to address urgent questions, dispel misconceptions, and direct individuals towards further training and resources.

FASD Awareness, through their **#BeAware** campaign, provides tailored training and presentations across various sectors. Their high-quality educational videos, case studies, insights from lived experiences, and exceptional presentation skills make their training sessions both engaging and memorable. Over the past decade, there has been a significant increase in understanding of Autism and ADHD, leading to improved support and more favourable diagnostic and therapeutic outcomes. It is crucial that FASD receives similar attention and understanding.

“The presenters were knowledgeable and interesting, and their own lived experiences were powerful reminders that we are all trying to learn to do better by the families and young people affected by FASD. The use of video and the voice of the young people, young adults that have the diagnosis was especially moving.”



“It was an excellent webinar, will definitely raise awareness, and yes now we raise a case with Commissioners in our area. We appreciate all your great work with this vulnerable group.”

Khadija HIMID, (OXLEAS NHS FOUNDATION TRUST)

Thank you so much for a wonderful presentation and raising awareness of FASD for the SEL health professionals. It was very informative and educational and it's going to help us tremendously to build a strong business case when we approach the commissioners to start services in our area! Keep up the good work and we are very proud of you all!”

Dr Sonia Shetty, Designated Doctor for Bromley CLA, School Doctor for Riverside SPC

10/10! What a great friendly presentation

Excellent. Ran smoothly, good use of videos and guest speakers with lived experience, good flow and kept interest. Lived experience accounts = very powerful - learning from this will stay with me.

It went beyond what I was expecting and brought the Syndrome to life.

This was a great presentation that shared and updated information about FASD in a way that could be easily followed.

CONNECTION & RELATIONSHIP

Friendship, awareness, support and community remains at the heart of FASD Awareness ethos. Following a series of questions from our survey monkey questionnaires, we have gleaned the following information.

1. **100%** of registrants are satisfied with FASD Awareness' services
2. Since registering with FASD Awareness **90%** have a greater understanding of Foetal Alcohol Spectrum Disorders?
3. Since registering with FASD Awareness only **50%** say they feel less isolated?

1. **98%** of registrants would recommend FASD Awareness' services
2. Since registering with FASD Awareness, **70%** have increased their networks of contact and/or friends within the FASD community
3. Since registering with FASD Awareness, **65%** feel more supported and confident in managing FASD behaviours.

Lessons to learn from responses to some of the questions

"It's a shame that we don't live in Kent so can't join the in-person activities as often as we would like to."

"A lot of the support group times and meetings are when I can't attend during the day because of work."

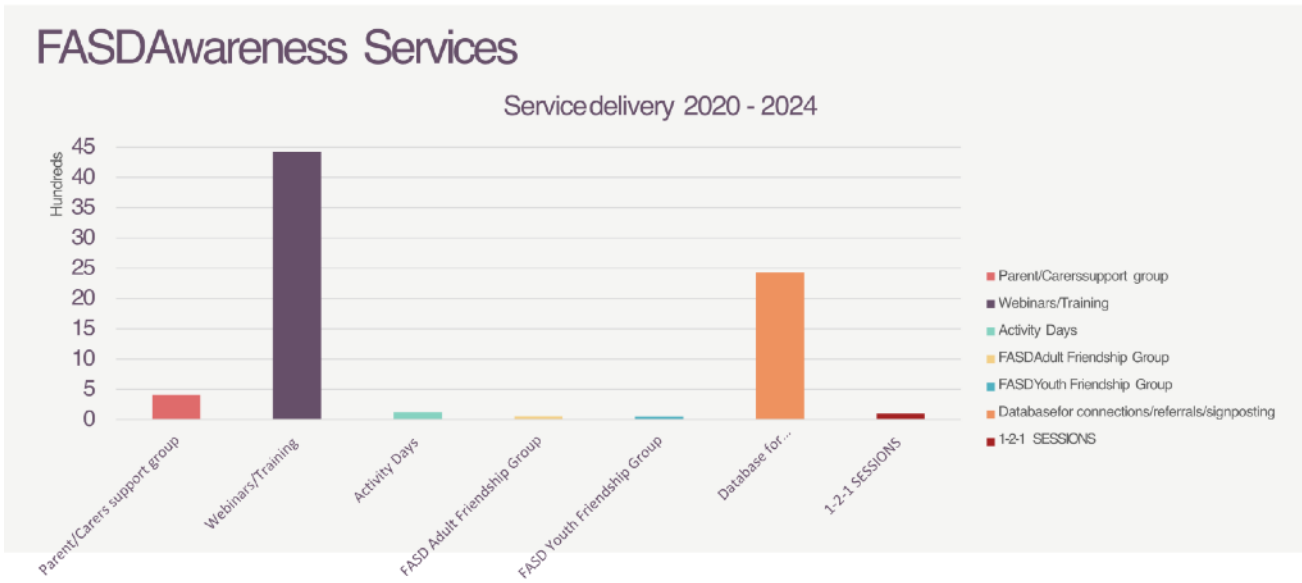
"I know there is support but too stressed and exhausted to do it.."

"The events are usually on a Thursday so I don't get to join them."

"Only because I don't have time literally not a minute!"

GROWTH & SUSTAINABILITY

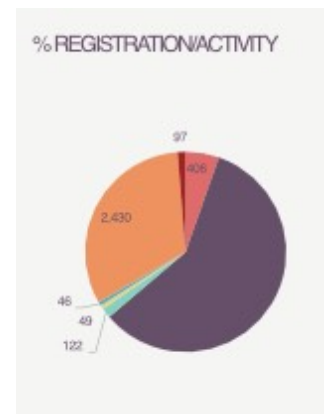
Throughout the Covid pandemic, many of our families reached out for additional support and guidance. In response, we swiftly adapted our services to include online support groups. The positive outcomes from these groups led to the introduction of one-to-one emergency sessions and a strong interest in establishing Youth and Adult Friendship groups. The increased visibility and marketing efforts following the pandemic resulted in a significant rise in registrations. Our Leeds Castle Activity Days had always been a favourite among families prior to lockdown, although we faced



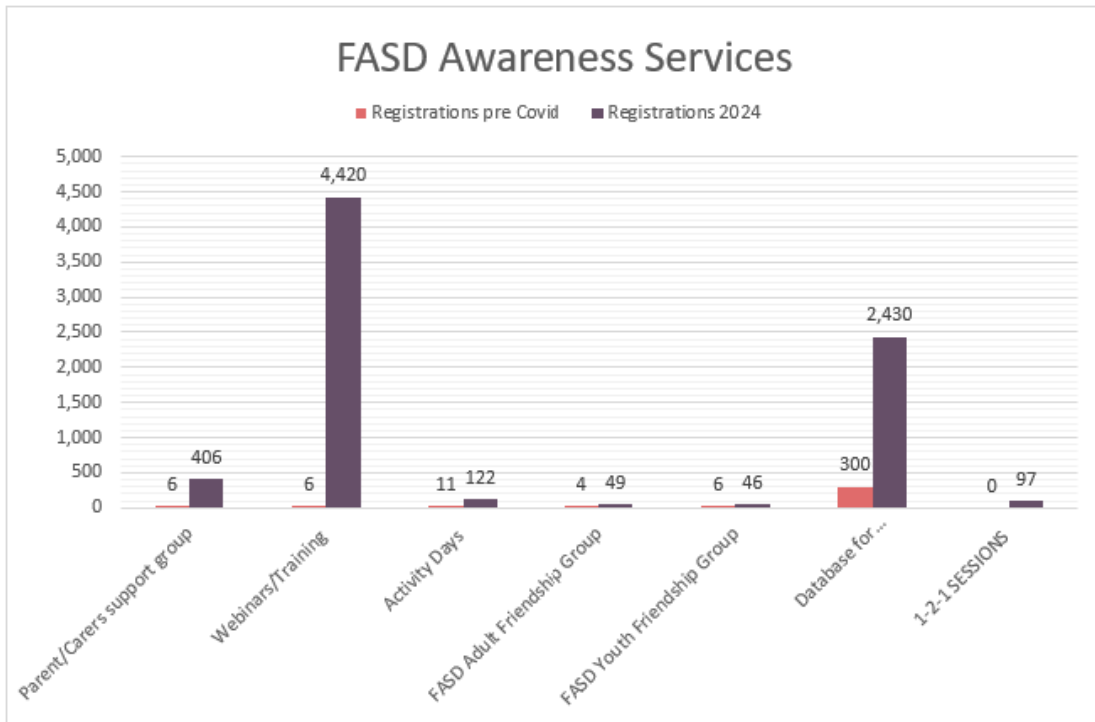
Item	Registrations pre Covid	Registrations 2024	Registrations 20242
Parent/Carers support group	6	406	406
Webinars/Training	6	4,420	4,420
Activity Days	11	122	122
FASDAdult Friendship Group	4	49	49
FASDYouth Friendship Group	6	46	46
Databasefor connections/referrals/signposting	300	2,430	2,430
1-2-1 SESSIONS	0	97	97
Total			7,570

N.B. - FAMILIES figures can include up to 5 per family and a minimum of 2.

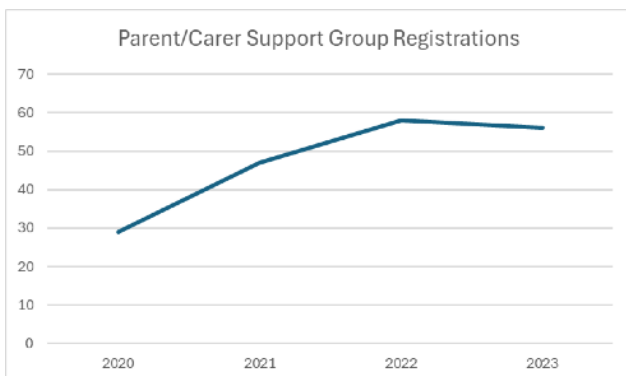
limitations on attendance at each event. Thanks to increased funding in 2021, we were able to expand the number of these events throughout the year.

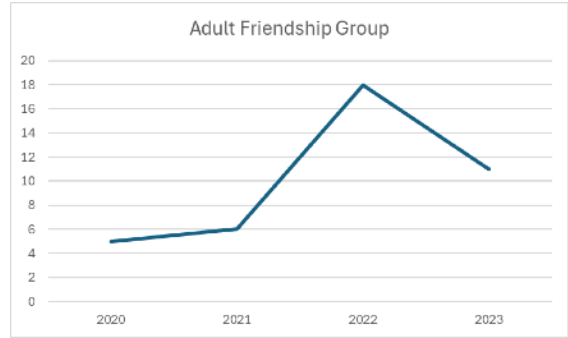
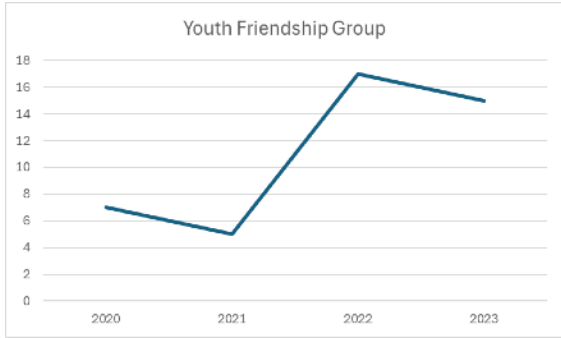


As the world shifted online during the lockdowns, we recognized an opportunity to deliver educational webinars. Through a targeted marketing campaign, we experienced a significant rise in registrations on Eventbrite, which also allowed us to build a larger database for promoting our services both nationally and internationally. By uploading the webinars to YouTube, we observed that the FASD Community worldwide shared them, positively enhancing our brand identity. In 2022, we faced an unexpected loss of a vital funding stream from the Kent & Medway ICB. This setback, combined with reduced funding from existing Trusts and Organizations, led us to



streamline operations. Our dedicated staff worked without pay for several months until we improved our financial situation through successful funding applications. Although we maintained an increase in registrations and service delivery, it did not match the previous years' pace. However, in the first quarter of 2024, we have observed a renewed increase. In May 2024, we have bought in a team from First Business





Solutions, to help FASD Awareness improve our growth and development for the future in line with our Strategic Business Plan.

#BEAWARE FILM CAMPAIGN

We take great pride in the films produced for our **#BeAware** campaign. We are fortunate to have award-winning filmmaker Max Blustin from *New Planet Film & Media* on our team, whose expertise and ongoing commitment to our campaign result in visually stunning content, complemented by high-quality sound from *KeepingMedia*. Additionally, we have hosted a series of webinars featuring prominent figures in the FASD Community, addressing crucial topics that require attention. All our content is available for viewing on our YouTube channel linked below:

FASD FILM LINKS - (CLICK ON THE FILMS BELOW)



ADVOCATES OF FASD AWARENESS

FASD Awareness through our positive support and promotion of young people living with FASD, has helped give a platform to some of today's leading advocates of FASD around the world. Our support of these individuals and promotion of their achievements have helped forge a more positive outlook of what can be achieved with the right motivation and wrap-around support network. Here are some of those leading advocates and FASD Ambassadors. Maggie May winner of the coveted **Starfish Award** for International FASD Advocacy. Ruby McDonlad multiple award winner including **BBC Sports Personality of the Year Unsung Heroes Award 2023**. Rossi Grffin winner of the **National Diversity Award 2024** (ITV Glow Up).



Upper left: Maggie May
Upper right: Steven McGirr
Lower left: Rossi Griffin
Lower Middle: Ruby McDonald.
Lower Right: RJ Formanek

COLLABORATIONS & PARTNERSHIPS

FASD Awareness is proud to be a member of the **FASD UK Alliance**, which is a coalition of groups and individuals from across the UK who are united together for positive social change for those with Foetal Alcohol Spectrum Disorders (FASD). We are regularly invited to sit on round table meetings of specialists of FASD alongside the National FASD Experts Committee and Trustees, and leading policymakers, paediatricians, psychiatrists, GPs, commissioners, public health experts, researchers, and leaders from the Third Sector with lived experience. FASD Awareness were stakeholders in the FASD Nice Quality Standards published in 2022. We were a part of the team leading to the *“Time is Now” document* - The National Perspective, Ramping up FASD Prevention, Diagnosis & Support Services. We are part of the **International FASD Share Collaborative** and are regular guests on webinars worldwide. FASD Awareness has been invited to sit on the **All-Party Parliamentary Committee on FASD**.

In 2019, FASD Awareness, in collaboration with Kent & Medway Clinical Commissioners and Dr Raja Mukherjee (Consultant Psychiatrist, Adult Learning Disability Consultant Psychiatrist for Surrey and Borders' Partnership NHS Foundation Trust) set up the first Hub and Spoke Model in the UK, up-skilling Community Paediatricians in diagnosing FASD. Additionally, their continued collaboration with the CCG and a push for a provision to cater for FASD Families in the South East of England has resulted in the formation of the Kent and Medway Foetal Alcohol Spectrum Disorder (FASD) System Partnership Group.

Throughout 2023/4, we have led an **‘Experts Committee on FASD in the Criminal Justice System’**. This is a steering group of many of the leading figures in the FASD community, alongside probation, judiciary, legal, police and medical services. This group has been created by FASD Awareness to investigate the impact of FASD within the CJS.



FASD Awareness were awarded the **High Sheriff of Kent's Award** in 2019, for their work in the community.

In 2024 we were invited to be part of the EUFASD Alliance. The

European FASD Alliance was founded in 2011 to meet the growing need for European professionals, caregivers and NGOs concerned with FASD to share ideas and work together.

FASD Awareness believes passionately in collaborations with other charitable organisations. Locally, we link with **Medway Voluntary Action** and **Medway Neurological Network**. We are part of **Kent Police's Independent Advisory Group**, a group of community volunteers who work with Kent Police to improve policing services across the county, acting as critical friends.

In September 2024 the FASD Awareness team were awarded the **Judges Special Recognition Award** at the prestigious [Kent Charity Awards](#). It was a great honour for all the team to receive this award.



DONORS, CORPORATE PARTNERS & FUNDING SUPPORT

We are delighted to be supported by the local community, with corporate partnerships and monthly donors coming on board, as well as funding sources being sought out and achieved to ensure that awareness of FASD increases and the valuable support we provide continues.

We are so grateful to all who have supported FASD Awareness, be it a school charity day, running in a charity event, a wing walk, a Facebook Birthday donation, buying a cookie, or via our donate button on our website. Every contribution goes into supporting those in our FASD Community.



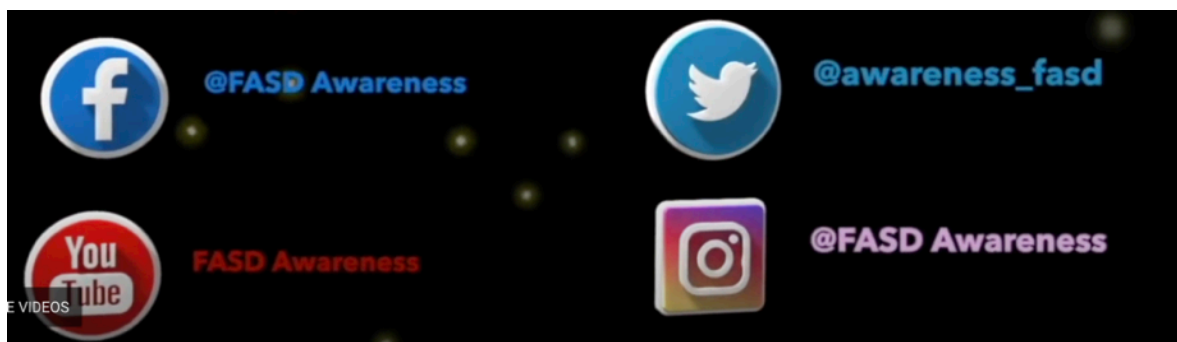


EQUALITY & DIVERSITY

Our charity FASD Awareness is committed to promoting equality, diversity, and inclusion by ensuring that all voices within the community are heard and valued. We actively create programs that cater to the unique needs of individuals from diverse backgrounds, fostering an environment where everyone feels welcome and supported.

FASD can affect people from any cultural background and from any social background, we actively welcome any individual or family living with fetal alcohol spectrum disorders.

You can find us on social media, please follow us to keep up to date with our work:



Facebook - @FASDAwareness

Instagram - @fasd_awareness

YouTube – FASD Awareness

LinkedIn- @fasdawareness

Twitter – @awareness_fasd

If you'd like to know more about FASD Awareness and/or to get involved, we'd love to hear from you. You can email us at info@fasdawareness.org.uk, or telephone 01634 566323.

Thank you for taking an interest in reading this report.

Kind regards

A handwritten signature in black ink, appearing to read "Andrew Kipping". The signature is written in a cursive style with a horizontal line underneath.

CEO of FASD Awareness
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andrew@fasdawareness.org.uk

FASD Awareness is registered as a CIO in England and Wales with Charity Number 1176933