

Activities of importance in 2022 and 2023, presentation of the organization and current board.

Invitation to General Assembly 2024

### The EUFASD Alliance

The EUFASD Alliance is a non-profit organization registered with the Tax Authority in Sweden in 2011.

The organization is a legal entity with organization number 802459-2654.

Book-keeping and accounting has been handled by Talenom authorized accounting agency.

Signatories in 2022 and 2023 have been Katarina Wittgard, Theresa Millqvist, Oscar Garcia-Algar and Simona Pichini.

The association's bank is Handelsbanken in Landskrona, Sweden.

In 2023, the EUFASD Alliance counted 42 member organizations from 21 countries.

The board has held 6 meetings by Zoom during 2023.

#### The board 2023

The board was elected at the General Assembly held at the Clarion Hotel Tyholmen in Arendal, Norway, in September 2022.

- · Oscar Garcia-Algar, Spain, chair
- Simona Pichini, Italy, vice chairperson
- Marta Astals, Spain, secretary
- Martha Krijgsheld, Netherlands, vice secretary
- Katarina Wittgard, Sweden, treasurer
- Theresa Millgvist, Sweden, vice treasurer
- · Magdalena Borkowska, Poland
- · Teodora Ciolompea, Romania
- Mirjam Landgraf, Germany
- · Gisela Michalovsky, Germany
- Thierry Maillard, France
- · Jon Skranes, Norway

Former chair Diane Black was appointed as permanent honorary chair at the General Assembly in Arendal 2022. Diane also serves as senior advisor for the EUFASD Alliance.

During the latter part of 2023 Oscar Garcia Algar left the post of chairperson. Vice chair Simona Pichini replaced Oscar as signatory.



**Simona Pichini** Pharmacotoxicologist working at the Italian National Institute of Health. Acting Director National Centre on Addiction and Doping, expert of pharmacokinetics and toxicokinetics of classical drugs of abuse, new psychoactive substances and doping agents in conventional and nonconventional biological matrices. International experts in monitoring ethanol exposure biomarkers in newborns, children, adults and pregnant women in correlation with clinical outcomes.

Contact: simona.pichini@iss.it



**Marta Astals Vizcaino i**s a graduated Psychologist specialized in Learning Disabilities and Neurodevelopmental Disorders. She has been a researcher on FASD field since 2016. Marta also coordinates the FASD clinic at Barnaclinic (Hospital Clinic). She has participated in the development of several clinical guides, books and training courses about FASD in collaboration with the main FASD organizations and government institutions from Spain.

Contact: marta.astals@gmail.com



Martha Krijgsheld
Chair and founder of the Dutch FASD Stichting (founded in 2002)
Foster mum of 4 children with FAS.
Board member of the FASD Alliance since 2010.
Contact: marthakrijgsheld@gmail.com



**Kafarina Wiffgard**, founder of the Swedish FAS association in 2000, operational manager of the organization. Creator of the Nordic region's only website with quality-assured information about FASD, funded by the National Board of Health and Welfare. Adoptive parent of a 37-year-old son with FAS and two daughters. Former foster parent and work in social services with support for families and young people. Studies in sociology and social psychology at Lund University. Author of information and educational materials about FASD. Contact: katarina.wittgard@fasforeningen.se



Theresa Millqvist, Sweden.
Chairperson of Swedish FAS-föreningen and vice treasurer at EUFAD Alliance.
Adoptive mother of a son with FAS.
Contact: theresa.millqvist@gmail.com



Magdalena Borkowska has her expertise in the field of public education and prevention. She is a Head Specialist in charge of prevention and public education in The National Center for Prevention of Addictions and Academic Lecturer in the field of Clinical Psychology and Health Psychology. Authors of the Magazine Nurses and Midwives published by the Supreme Chamber of Nurses and Midwives in Poland. Research Interest: Prenatal Alcohol Exposure (PAE) - prevention, diagnosis and therapy; Clinical Psychology and Psychooncology; Holistic Approach to the Individual.

Contact: magdalena.borkowska@kcpu.gov.pl



**Teodora Ciolompea** MD. Specialized in prevention and treatment of alcohol and drug addictions. Master's degree in public health. Works with addicts and families in hospitals and ambulatory system. Expert for the Ministry of Health on Mental Health policy, national and EU legislation and treatment facilities development. Involved with Ministry of Education in health promotion and health education campaigns. Creator of educative materials and trainer on mental health promotion for family doctors, social workers. Representative for Ministry of Health Romania on EUROCARE.

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Oscar Garcia-Algar, Paediatrician, head of Neonatology Unit, researcher at IDIBAPS and coordinator of research and innovation at the neonatology Hospital Clinic, Barcelona. Full Professor of paediatrics, Universitat de Barcelona. CSO of Psicoterapia VR. His expertise is about clinical effects of prenatal exposure to substances of abuse (mainly alcohol), and FASD (including epidemiological, clinical and research studies), and maternofetal environmental medicine. Contact: ogarciaa@clinic.cat



Mirjam N. Landgraf, Paediatrician, child neurologist, psychologist. Senior resident, Head of the Special Outpatient Clinic for Children with toxin exposure during pregnancy, Head of the German FASD COMPETENCE CENTRE Bavaria (www.deutsches-fasd-kompetenzzentrum-bayern.de), Ludwig-Maximilians-University Munich, Germany. Coordinator of the German FASD Guideline and of several healthcare research projects on FASD. Federal Representative for FASD of the Society for Neuropaediatrics (Germany, Austria, Switzerland). Contact: mirjam.landgraf@med.uni-muenchen.de



**Gisela Michalowski** is a foster mother of 5 children with FASD, adoptive mother of a son with FASD and mother of 4 of her own children aged 9 to 42. Since 2005, she has been a member of the board of FASD Germany. She works as a social worker in a youth welfare facility since 2010. She has been wearing the Federal Cross of Merit of the Federal Republic of Germany since 2023 for special voluntary services in favor of people with FASD. Contact: giselamichalowski@fasd-deutschland.de



**Thierry Maillard** General Practitioner and Addictologist in Reunion island. Founder and chair of feu Reunisaf since 2001, first network in France for FASD prevention, for families and professionals. Founder and chair of SAF Ocean Indien till 2011. Founding member of European FASD Alliance. Founding member and vice chair of Africa FASD since 2023.

Contact: docteur.thierry.maillard@wanadoo.fr



Jon Skranes Senior paediatrician in Regional Competence center for children with prenatal alcohol and/or drug exposure and head of Child Habilitation Centre, Department of Pediatrics, Sørlandet Hospital Arendal, Norway. Adjunct professor at the Department of Clinical and Molecular Medicine, Faculty of Medicine and Health Sciences, Norwegian University of Science and Technology (NTNU) in Trondheim. His research work is linked to affected early brain development in neonatal risk children, especially preterm children and children with prenatal alcohol/drug exposure.

Contact: jon.skranes@sshf.no

### **Auditors**



**Merete Haugen.** I have a master's degree in family therapy and systemic practice. I have many years of experience from the specialist health service and cooperation with relatives and various municipal services. I represent one of the Drug and Alcohol Resource Centres (KORUS) in Norway. Contact: merete.haugen@korus-sor.no



Antoine Bourely, Vivre avec le SAF, France Adoptive parent of a boy with FASD, now 33 years old. Founder of Vivre Avec le SAF, together with wife Catherine Metelski, to offer a French speaking forum on FASD. Creator of a guidebook for parents, translate and adapt American litterature. PhD in Automation, Chief Scientific Officer in a private company manufacturing optical sorters for recycling. Expertise in machine vision and artificial intelligence, both relevant topics for FASD diagnosis. Contact: bourelski@gmail.com

### Election committee



Jan de Vries, Netherlands

Registered Psychologist Child & Adolescent, Orthopedagogue-generalist BIG, EMDR Practitioner, Supervisor Child-Adolescent Psychologist, Practical Trainer, Researcher, Certified Advanced Practitioner Sensorimotorpsychotherapy. Contact: jan@zo-zorgoplossingen.nl



**Professor Raja Mukherjee** is an Adult Learning Disability Consultant Psychiatrist for Surrey and Border's Partnership NHS Foundation Trust, with interest in the management of developmental disorders across the lifespan. In September 2009. Raja is an Internationally recognised expert clinician and researcher in FASD, with nearly 80 academic publications related to FASD. He has advised many groups and been part of the EUFASD movement from its inception. Prof Mukherjee was awarded an MBE for his work related to FASD in the Kings Birthday Hours list in June 2023.

Contact: raja.mukherjee@sabp.nhs.uk

# Conference report EUFASD 6

The sixth European Conference on FASD took place on September 12 to 14, 2022, with a pre-conference training day on 11 September and a satellite conference on the EU-funded FAR SEAS project on Tuesday, September 13.

The conference was held at the Clarion Hotel Tyholmen in the seaside Norwegian village of Arendal. Despite some frustrations with delayed flights and sometimes long bus rides from Oslo, all were charmed by the location.

At the pre-conference training day there were 51 participants. At the main conference there were 252 participants, representing 30 different countries from around the world. The FAR SEAS Satellite workshop, building on the stimulating talks and ideas presented in the wider EUFASD conference, brought together 54 participants from over 19 European countries for a 1-day workshop of two sessions. The morning FAR SEAS session focused on practical issues and options for making large-scale prevalence estimates of FASD, including issues of data collection, prevalence among different population groups, ethical issues of such studies, and how to communicate and use the results to maximum effect; and the afternoon session, looked at how to move on from establishing the prevalence to prevention initiatives to reduce prenatal alcohol exposure, whilst safeguarding women's and families' confidentiality and providing ethical treatment and support.

Participants from clinical, public health, academic and civil society backgrounds came together to listen to the latest evidence in these areas and share their insights in interactive discussions. The outputs from the workshop - the introductory presentations and a workshop report with conclusions - will be available on the FAR SEAS website (www.far-seas.eu/capacity-building/) in October, and later through the EC webpages and Health Policy Portal.

# Scholarships

Three scholarships were offered to attend the conference.



Babatope Adebiyi presented a talk on "A guideline for the prevention and management of Fetal Alcohol Spectrum Disorder in South Africa." He says "The conference allowed me to meet and network with leaders in FASD research. All thanks to the organisers and sponsors."



Froukje Wielenga presented a poster entitled "A Management Program for Children and Adolescents with Fetal Alcohol Spectrum Disorders in the Netherlands: a Research Proposal."



Miranda Eodanable presented her work in a poster entitled "Experiences of young people with Fetal Alcohol Spectrum Disorder: a photovoice study." Miranda says "The EUFASD scholarship has provided me an invaluable opportunity to meet with an international network of researchers and to reflect on their dynamic research. The sessions and informal discussions will continue to direct my journey as a PhD researcher and an educational psychologist. Thank you!"

The following poster prizes were awarded

First Prize. Poster 38: Sharon Dawe, Elizabeth Eggins, Joseph Lee Betts, Heidi Webster, Denise Hatzis, Tania Pomario, Hayden Tills, Ned Chandler-Mather, Doug Shelton: Assessment of young children with prenatal exposure: Knowledge gained and challenges ahead - from Australia.

Second Prize. Poster 47: Silje Lunderød, Sara Greger, Gislaug Søyland Sele, Linda Jensen, Elise Hærem: The founding of the organization FASD NORGE - from Norway.

Third Prize. Poster 31: Madeline N. Rockhold, Carson Kautz-Turnbull, Christie L.M. Petrenko: Threat versus deprivation trauma exposure and behavioral outcomes in children with fetal alcohol spectrum disorders - from the United States.

## Activity report 2023

The main activity of the year 2023 was preparations for the EUFASD Conference in Madrid 22<sup>nd</sup> to 25<sup>th</sup> of September 2024.

Oscar Garcia Algar worked with the planning together with representative from the Spanish organization VisualTEAF. Jacinto Castillo from VisualTEAF presented the organizational activities and the budget at a board meeting and informed that the Spanish Ministry of Health gave their support for the conference, both financially and with locations and catering at the ministry.

The board was involved in the work of appointing a scientific committee, assessing abstracts, etc. Practical implementation of the conference was entirely up to Visual TEAF in collaboration with the organizer they chose for the assignment. The EUFASD Alliance made no financial commitment for this conference.

The board decided that Diane Black should be invited as honorary guest at the conference in Madrid. One of the poster prizes will be named after Diane Black.

## The new website and logo

The EUFASD Alliance needed both a new website and new logo, the original ones were more than ten years old. Financing of a professional website was possible thanks to the surplus that was generated by the conference in Arendal, Norway, previous year.



The board worked during the fall of 2023 with various ideas and proposals regarding both content and design. A favourable quote was provided by the web agency INKA Interactive in Malmö, Sweden, which offered a 50% discount to support the EUFASD Alliance. The board decided to accept the offer and by the end of the year both the website and logo were in place.