

<p>Year of report: 2021-2022</p>	
<p>Name of Working Group: Mental Health Working Group Subgroups: Treatment group & Research group</p>	<p>Date of initial approval of working group: Starting date: June 2016 Extension date: June 2019 Extension date: June 2022</p>
<p>Contact details of coordinator, vice coordinator and assistant (if applicable) including ECFS membership numbers:</p> <p>Coordinator Treatment group: Name: Edwina Landau</p> <p>Coordinator Research group: Name: Marieke Verkleij</p>	
<p>Long term aims of the working group (maximum 100 words) including estimated achievement date:</p> <p>Aims:</p> <ol style="list-style-type: none"> To develop a multidisciplinary network of clinicians and researchers to facilitate and support the dissemination and implementation of the Mental Health Guidelines. To monitor the implementation of Mental Health Screening and identify the range of clinical practice and treatment referral pathways across Europe. To determine patient and parent-reported effectiveness / impact of MH Screening and Care. To promote preventative mental health strategies, resilience and emotional wellness To promote excellence in Mental Health research across the European CF Community. 	
<p>Outcomes already achieved (maximum 100 words):</p> <p>During this second term, many of the aims and objectives have been met. The MHWG has engaged with the European CF community (CF health professionals / centres, patients and caregivers). The MHWG is divided into two groups, the research group and treatment group, with both monthly Telco's and the AGM at the ECFS Annual Conference. To-date, the successful activities of the Working Group have established mental health CF professionals, from Eastern and Western European countries, who can assist with the group's activities. This has helped to disseminate and implement the Guidelines in many countries across West and Eastern Europe.</p>	
<p>Report for this year:</p> <p>The treatment subgroup has focused on the following aims:</p> <ol style="list-style-type: none"> Update on the website a list of evidence-based treatment modalities/ interventions for helping people with CF with depression and anxiety. Treatments European Cystic Fibrosis Society (ECFS) In collaboration with the mental health advisory committee in the US, Dr Anna Georgiopoulos as the US representative, handouts on a variety of prevalent topics are being shared and translated on the website (with permissions from the American CFF website, as well as handouts from Improving Life with CF project, and a stress first aid handout from the National Center for PTSD). These include, sibling, caregiver and parenting handouts, pain, procedural anxiety, coping with stress, parenting with CF etc. Resources European Cystic Fibrosis Society (ECFS) Expanded the work of the working group into more Eastern European countries, we have a representative psychologist from Russia who is coordinating and translating the resource material (sibling and caregiver support handouts) to Russian, Slovak, Slovenian. 	

- 4) We organized a series of training webinars, together with EPSIG (European Psychosocial Interest Group). This is called the CF lunch time series. We succeeded in reaching over 34 countries including Europe, Eastern Europe, Asia, USA as well as Australia and New Zealand. To date we have organized 9 webinars, looking forward to continuing after. This has enabled many countries to participate and be exposed to important current clinical topics affecting the world of mental health CF today.

Topics included:

- 1) Challenges and complexities of care in transition
- 2) Food and CF: Friend and Foe?
- 3) How covid-19 changed the clinic: learning as we move along in uncertain times
- 4) New challenges of care: physiotherapist and pharmacist joining forces
- 5) Women's health and cystic fibrosis
- 6) A basic introduction for allied health professionals into CFTR modulators
- 7) Pain in CF
- 8) Past, present and future psychosocial care in CF
- 9) Trauma and CF

The research group has focused on the following aims:

1. Survey to evaluate the impact of the MH guidelines from the patient/caregiver perspective.

We are interested in the importance that patients and caregivers put on mental health, their preferences and experiences of screening and any follow-up care.

First results: The initial survey monkey slides are provided on the website:

https://www.ecfs.eu/sites/default/files/general-content-files/working-groups/Mental%20Health?MH%20Survey%20Data_All_200128%283%29.pdf.

See abstract:

S. Graziano, E. Landau, Verkleij M, Anna M. Georgiopoulos, M. Schechter, Janice Abbott, Alexandra L. Quittner, Beth A. Smith (2021). Mental health screening in CF: Thematic analysis of determinants of implementation in Europe and the United States. J Cyst Fibrosis, abstract published on 01 Nov 2021.

Results and paper have been written up, awaiting publication together with colleagues from the CFF Mental health advisory committee. This research was presented as an oral presentation at the ECFS digital conference in June 2021, in the workshop 11 on 11.6: - **Anxiety and stress in cystic fibrosis through a challenging 2020 and novel interventions:**

Landau E, Verkleij M, Graziano S., Quittner A.L., Georgiopoulos A.M., Smith B.A., Schechter M.S., Abbott J. (2021). WS11.5 Mental health screening as an intervention: how patients and caregivers contribute to improving our processes. J Cyst Fibros. Abstract published on 01 Jan 2021.

MHWG contributions to the ECFS digital conference 2021:

Evidence based pre conference workshop course: (this is organized jointly with EPSIG): Power Threat Meaning Framework

Tomorrow's lounge: We are screening...now what? Different treatment modalities in CF mental health

Meet the Experts session: Psychological impact of not being eligible for new treatments.

Meet the Experts session: Impact of modulator Therapy

This year's contributions to the ECFS 2022 conference in Rotterdam together with EPSIG:

- **Pre-conference workshop:** Sex, intimacy and reproductive health in CF by Sexologist Paul Enzlin

- **Tomorrow's lounge** :Telehealth mental health screening and treatment during COVID-19--Is it here to stay?
- **Meet the expert sessions:** How to cope with the fast lane and also the slow lane: caring for patients t are not eligible and those who are eligible for CFTR modulator.

Summary and Aims

- Maintaining, and updating of the Mental Health Website including translating more resource handouts from the USA CFF including management of pain, parenting coping skills and CFTR modulator psychosocial short term and long-term considerations
- Further language translations of the documents for MDT clinician (all clinicians in the CF Team), particularly in those regions with less resources
- Documenting MH provision/care paths and best practice
- Evaluating the psychological effects of CFTR modulators in Europe
- Continuing implementing the MH guidelines in Western and Eastern Europe
- The MHWG will focus on promoting preventative strategies, resilience and emotional wellness.

Breakdown of expenses for the year:

Income: ECFS Support: 10,000 Euros

Expenses: Support Speaker course, telco: 464 Euros

Remaining income: 9,536 Euros

Support speaker for this CF 2022 preconference program as well as holding the Mental Health Working Group meeting during ECFS Annual Conferences (15-20 participants). Total: about 1500 Euros

Budget amount requested for next year (please give the amount in Euros and the year): 10,000 Euros

- Organisation of meetings/networking events, minute meetings, produce newsletters/report, liaison with ECFS, CF Centres and Patient Organizations
- Manage website resource content
- Continuation of collaboration with the US Mental Health Advisory Committee

In collaboration with the EPSIG

- Future pre conference training workshops
- Bi-monthly lunch time webinars