Annual Report ECFS Mental Health Working Group

Overall summary of the last year 2019-2020

Coordinators:

Dr. Eddie Landau - Israel (Psychologist) eclandau@gmail.com
Dr. Marieke Verkleij – Netherlands (Psychologist)
m.verkleij@amsterdamumc.nl

Participants:

Janice Abbott – UK (Psychologist) jabbott@uclan.ac.uk
Urszula Borawska – Poland (Psychologist) urszula.borawska@imid.med.pl
Anna Georgiopoulos - US (Psychiatrist) ageorgiopoulos@partners.org
Sonia Graziano-Italy (Psychologist) graziano.sonia@gmail.com
Riccardo Ciprandi – Italy (Psychologist) ric.cip@libero.it
Trudy Havermans - Belgium (psychologist) trudy.havermans@uzleuven.be
Pavla Hodkova - Czech Republic (Psychologist) pavla.hodkova@seznam.cz
Stina Järvholm – Sweeden (Psychologist) stina.jarvholm@vgregion.se
Diana Kadosh – Israel (Social Worker)) dianakadosh64@gmail.com
Annette Katscher-Peitz – Germany (Psychologist) a.katscher-peitz@klinikum-stuttgart.de
Johanna Gardecki – Germany (Psychologist) johanna.gardecki@kgu.de
Maya Kirszenbaum – France (Psychologist) maya.kirszenbaum@nck.aphp.fr
Jaquelien Noordhoek – European Parent Association (parent) j.noordhoek@ncfs.nl
Yvonne Prins – Netherlands (Adult with CF) yvonne@yvonneprins.nl
Ulrike Smrekar – Austria (Psychologist) Ulrike.Smrekar@uki.at
Ralf Thalemann- Germany (Psychologist) ralf.thalemann@charite.de
Olga Polaetva – Russia (Psycholgist) poletaeva.olga25@gmail.com

The ECFS Mental Health Working Group has divided into two subgroups:

1. **Treatment/intervention group, coordinated by Edwina Landau**
2. **Research/evaluation group, coordinated by Marieke Verkleij**

The two subgroups have monthly tele-conferences and continue to develop a network of CF Health Professionals who act as ‘Country Captains’, assisting with the collection of country specific information.

Treatment/Intervention Group

The treatment/Intervention subgroup has focused on the following areas this year:

- Follow up of treatment guidelines
- Developing the resource area on the ECFS website to provide easy access to resources to facilitate implementation of MH screening in many European languages.
- Making treatment available also for low resource countries
- Flyers with links to website, resources in different languages
- Peer support network and sharing experiences
- Extending the focus on positive psychology
- Providing opportunities for training

In particular:

1) We have added additional resource material to the website including the sibling and caregiver handout from the American CFF website (currently being translated into many different languages).

2) We are documenting different treatment modalities/ interventions for helping people with CF with depression and anxiety to be put on the website in the coming month. Examples of different treatments include: ACT, existential therapy, CBT, mindfulness, play therapy, psychodynamic therapy, parent centered therapy, systemic family therapy, psycho-analytic therapy, IPT, parent management training, DBT.

3) We have been working on expanding the work of the working group into more Eastern European countries, with CF-psychosocial lectures in Kiev at the South Eastern CF Congress in September 2019 by Marieke Verkleij and presenting a state of the art in CF Mental Health and networking at the Young Investigator Meeting in Paris (Feb 2020), as well as welcoming this year to the MHWG a mental health representative from Russia.

4) In addition, due to the Corona crisis, we have set aside time in the teleconference meetings to provide support to one another during this challenging time, sharing our individual experiences in our respective countries.

Research Group

Currently running in Europe and the USA: *Survey to evaluate impact of the MH guidelines from patient /caregiver perspective* .

Health professionals have reported that MH screening has been successfully implemented in many CF Centres. From this data, we now have some understanding of the benefits and barriers of mental health screening. To complete this picture, we are interested in the importance that patients and caregivers place on their mental health, their preferences and experiences of screening and any follow-up care.

Publication ECFS MHWG 2019:
Abbott J, Havermans T, Jarvholm S, Landau E, Prins Y, Smrekar U, Staab D, Verity L, Verkleij M; ECFS Mental Health Working Group. Mental Health screening in cystic fibrosis centres across Europe. J Cyst Fibros. 2019 Mar;18(2):299-303.

The International Mental Health Guidelines Committee (IMHGC) in Cystic Fibrosis set up consensus statements for screening and treating depression and anxiety in individuals with CF and their caregivers. These statements are advocated in the published guidelines. The guidelines were informed by feedback from the CF clinical, parent and patient communities in Europe and the US. They recommend annual anxiety and depression screening for adults and adolescents (12+ years), and at least one primary caregiver of children under 18 years.
If resources are available, annual interview assessment for all participants would be the ideal. This is not possible in many centers but the screening tools are easy to administer, and providing referral pathways are available. Therefore they can be valuable where time is limited. The screening tools recommended by the ICMH, the Patient Health Questionnaire 9 (PHQ-9) for symptoms of depression and the Generalized Anxiety Disorder Scale (GAD-7) for anxiety have been shown to be suitable in general populations. The Mental Health Guidelines provide a valuable first step in recognizing, addressing and improving the mental health of CF families.

The research subgroup has focused on the following areas this year:

1) Positive psychology and the strengths of CF-patients and caregivers which may reduce the burden of CF. Therefore, resilience is one of the topics which should be taken into account when screening for psychological distress. **Current research projects resilience**: Brief Resilience Scale (BRS) (Smrekar, Verkleij).
2) Screening of psychosocial problems in younger kids with CF < 12 yrs. and family functioning may prevent adolescents from anxiety and depression, since psychological interventions can start at earlier stage. **Current research projects: A. Screening younger children < 12 yrs.:** → SDQ. **Family functioning:** children with CF, their siblings and caregivers: **PAT**-CF.
3) To gain more insight into specific CF-related complaints, since they can be associated with psychological distress. **Current research projects:** Gastrointestinal symptom tracker (Graziano, Verkleij)

Update per country 2019-2020:

AUSTRIA: Ulrike Smrekar, E-mail: ulrike.smrekar@tirol-kliniken.at
A crucial precondition for the implementation of the mental health guidelines, namely personnel resources, has improved over the last two years. Especially the time psychologists are dedicated to CF care has increased and an acknowledged working group - psychosocial staff in CF care in Austria - has been established.
MH screening is still routine only at the Innsbruck CF center. But other centres are thinking of starting MH screening, therefore psychologists from these centres visited the CF Center in Innsbruck in order to shadow the screening process.

In several Austrian CF-specific events the topics mental health guidelines, screening of anxiety and depression and treatment were of central importance.
The Austrian carer organisations attach great importance to this topic and support patients by e.g. financing psychotherapeutic treatment.
An information leaflet on MH guidelines and screening is available in German and is handed out. In the context of evaluating the longtime effects of psychosocial variables linked to illness trajectory, main psychological research interests of the CF centre Innsbruck are into CF, resilience factors and the role of positive emotions in psychological well-being and adherence strategies. Remote psychosocial support and intervention for the personalisation of adherence and coping behaviors is another topic.

Mitmansgruber H, **Smrekaru U**, Eder J, Ellemunter H (2019) Predicting psychological well-being and symptoms in adults living with cystic fibrosis: the role of self-compassion and psychological resilience. [poster] ECFS, Liverpool, UK, June.

BELGIUM: Trudy Havermans, E-Mail: trudy.havermans@uzleuven.be

- ✓ Boon M, Calvo-Lerma J, Claes I, **Havermans T**, Asseiceira I, Bulfamante A, Garriga M, Masip E, van Schijndel BAM, Fornes V, Barreto C, Colombo C, Crespo P, Vicente S, Janssens H, Hulst J, Witters P, Nobili R, Pereira L, Ruperto M, Van der Wiel E, Mainz JG, De Boeck K, Ribes-Koninckx C (2020). Use of a mobile application for self-management of pancreatic enzyme replacement therapy is associated with improved gastro-intestinal related quality of life in children with Cystic Fibrosis. J Cyst Fibros. 2020 Apr 22. pii: S1569-1993(20)30114-4.
- ✓ Boon M, Claes I, **Havermans T**, Fornés-Ferrer V, Calvo-Lerma J, Asseiceira I, Bulfamante A, Garriga M, Masip E, Woodcock S, Walet S, Barreto C, Colombo C, Crespo P, Van der Wiel E, Hulst J, Martinez-Barona S, Nobili R, Pereira L, Ruperto M, Vicente S, De Boeck K, Ribes-Koninckx C; MyCyFAPP consortium (2019). Assessing gastro-intestinal related quality of life in cystic fibrosis: Validation of PedsQL GI in children and their parents. PLoS One. 2019 Dec 20;14(12).
- ✓ Bell SC, Mall MA, Gutierrez H, Macek M, Madge S, Davies JC, Burgel PR, Tullis E, Castaños C, Castellani C, Byrnes CA, Cathcart F, Chotirmall SH, Cosgriff R, Eichler I, Fajac I, Goss CH, Drevinek P, Farrell PM, Gravelle AM, **Havermans T**, Mayer-Hamblett N, Kashirskaya N, Kerem E, Mathew JL, McKone EF, Naehrlich L, Nasr SZ, Oates GR, O'Neill C, Pypops U, Raraigh KS, Rowe SM, Southern KW, Sivam S, Stephenson AL, Zampoli M, Ratjen F (2020). The future of cystic fibrosis care: a global perspective. Lancet Respir Med. 2020 Jan;8(1):65-124.
- ✓ **Havermans T**, Willem L (2019). Prevention of anxiety and depression in cystic fibrosis. Curr Opin Pulm Med. 2019 Nov;25(6):654-659.

GERMANY: Ralf Thalemann, E-mail: ralf.thalemann@charite.de & Annette Katscher-Peitz, E-mail: a.katscher-peitz@klinikum-stuttgart.de

CF Research/ COACH
Adolescents with chronic illnesses are faced with a variety of challenges and sometimes have psychological stress such as depressed mood, worries and illness-related fears. There is currently little research on the optimal and early treatment of mental stress in adolescents with chronic illness. The COACH (Chronic conditions in Adolescence: Implementation and Evaluation of Patient-centered Collaborative Healthcare) network project is concerned with this topic. The main goal of the network is to develop and evaluate an interdisciplinary care model for chronically ill children and adolescents from

12-21 yrs who suffer from diabetes, cystic fibrosis or chronic arthritis. The CF subproject within the consortium aims for screening adolescents and young adults with CF for depression and anxiety to identify additional support needs. The impact of mental illness such as anxiety and depression on therapy adherence and clinical outcome will also be considered. For the treatment of psychological stress, an easily accessible, internet-based psychological therapy is developed and evaluat ed in another subproject.

ISRAEL: Edwina Landau, E-Mail: eclandau@gmail.com
Research evaluating how feelings towards cough and sputum production affects mental health (anxiety and depression) and compliance to treatment.

- ✓ **Landau, E**, Levine, H. Cough and sputum embarrassment in Cystic Fibrosis Patients. Israel Cystic Fibrosis Society. Presented at Bi-Annual National Meeting, Netanya, Israel, November 2019.

Efficacy of a Yoga Breathing Program on Quality of Life in CF patients
Research on how the use of simple yoga breathing techniques and postures influence the overall emotional and physical wellbeing of CF patients. This is awaiting Helsinki approval.

Screening of anxiety (GAD-7) and depression (PHQ-9) now being combined with the resilience scale (BRS) (translated to Hebrew) among CF-patients and parents.

Diana Kadosh: E mail:dianakadosh64@gmail.com
Diana is working on the translation to Hebrew of the CF-CBT intervention for anxiety and depression in adults with Cystsic Fibrosis with the intention to pilot a study in collaboration with Drs. Deborah Friedman and Anna Georgiopoulos

ITALY: Sonia Graziano, E-Mail: graziano.sonia@gmail.com
MH screening is a routine in the CF Center in Italy; screening of anxiety (GAD-7) and depression (PHQ-9) are combined now with HRQL (CFQ-R) and Gastrointestinal (GI)-Symptom Tracker (translated and adapted in Italian working with Alexandra Quittner). The study of Sonia Graziano “Rates of depression and anxiety in Italian patients with cystic fibrosis and parent caregivers: Implementation of the Mental Health Guidelines” is currently under review (Respiratory Medicine; Graziano et al.; 2020).
Sonia Graziano is currently working on translation to Italian of the CF-CBT Intervention for anxiety and depression in adults with Cystic Fibrosis (Manual and Workbook) with the intention to establish a pilot study research program in collaboration with Drs. Deborah Friedman and Anna Georgiopoulos. She attended the CF-CBT training in Boston together with Diana Kadosh and Marieke Verkleij (November 2019, Massachusetts General Hospital).

- ✓ **Graziano S**, Alghisi F, Ciciriello F, Lucidi V, Tabarini P, Quittner AL (2019). Italian Translation of Gastrointestinal (GI) Symptom Tracker in Patients with Cystic Fibrosis. Poster: ECFC 2019 – Liverpool, UK, June.
- ✓ Savi D, **Graziano S**, Majo F, Alghisi F, Montemitro E, Di Biase R, Bella S, Lancellotti S, Di Toppa MV, Tabarini P, Lucidi V (2019). Transition readiness, clinical and psychological variables in patients with cystic fibrosis: a single center experience in Italy. Poster: ECFS 2019 – Liverpool, UK, June.

- ✓ **Graziano S,** Ciciriello F, Alghisi F, Righelli D, Quittner AL, Boldrini F, Lucidi V, Tabarini P (2019). A CF Risk Factor Model: Gastrointestinal, Psychological Symptoms and Quality of Life in Cystic Fibrosis. Poster: NACFC, Nashville, TN,

POLAND: Urszula Borawska – Kowalczyk, E-mail: urszula.borawska@imid.med.pl
Urszula Borawska is involved in the project "Supporting and educating patients after CF diagnosis in their child" (various activities: workshops, support group, book, parent to parent; to help parents in the first years after diagnosis). Urszula Borawska received the CF Circle of Care grant and is currently preparing documents.
Urszula Borawska is also planning a summary of the results and consequences of screening in children and parents.

SWEDEN: Stina Järvholm, E-mail: stina.jarvholm@vgregion.se
In the four CF-centers in Sweden the work around psychosocial research and evaluation have lately been focused in implementing the screening and evaluate the results and patient acceptance. There has also been a national collaboration in creating robust psychosocial measures to annually report to the national CF-register. Areas of interest is for example how to develop easy pathways for help for the young adults with mental health issues and how to best support the increasing elderly group of adults with CF.

- ✓ **Järvholm S**, Ericson P, Gilljam M. (2020). Patient acceptance and outcome of mental health screening in Swedish adults with cystic fibrosis. Qual Life Res. 2020 Jan 9. doi: 10.1007/s11136-020-02417-5. [Epub ahead of print]

THE NETHERLANDS: Marieke Verkleij, E-mail: m.verkleij@amsterdamumc.nl
Focus on resilience: Screening of anxiety (GAD-7) and depression (PHQ-9) are combined now with the resilience scale (BRS) among CF-patients and parents.
Marieke Verkleij received the CF Circle of Care collaboration grant with Anna Georgiopoulos and Deborah Friedman (USA) to develop eHealth CF-CBT; an online cognitive behavioral therapy program for people with CF in Dutch and English. In 2020 she'll pilot the Dutch eHealth CF-CBT program in Amsterdam UMC with funding from the Dutch Cystic Fibrosis Foundation.
Marieke Verkleij is currently working on translation of the Gastrointestinal (GI)-Symptom Tracker into Dutch.

- ✓ **Verkleij M**, Geenen R, Landau E, van Dijk-Lokkart EM, Quittner A (2019). Improving treatment adherence in adolescents with cystic fibrosis: feasibility of the "CF My Way" intervention program. [poster] ECFS, Liverpool, UK, June.
- ✓ **Verkleij M**, Georgiopoulos A (2019). An International Collaboration to Adapt the MGH CF-Specific CBT Program for Prevention of Depression & Anxiety into CF Team Guided, Internet Delivered Modules in English & Dutch. [poster and oral presentation] Vertex 4th Annual CF Circle of Care Colloquium, Liverpool, UK, June.
- ✓ **Verkleij M**, Georgiopoulos A, Friedman D (2019). Development of a therapist-guided internet-delivered CBT Intervention for anxiety and depression in adults with Cystic Fibrosis (eHealth CF-CBT): An international collaboration. [poster and oral presentation] NACFC, Nashville, TN, Oct.
- ✓ **Verkleij M** (2019). Psychosocial aspects of CF. CF Europe. South Eastern CF Congress, Kiev, September.
- ✓ **Verkleij M** (2020). Human and Social Sciences- State of the art lecture. 14th European CF Young Investigators´Meeting Paris, Feb.

UNITED KINGDOM: Janice Abbott, E-Mail: JAbbott@uclan.ac.uk

- ✓ **CFF AWARD**

Professor Janice Abbott has received a prestigious international award from the Cystic Fibrosis Foundation. ***The Carolyn and Richard Mattingly Award*** is given each year in recognition of distinction. The award recognises research and leadership in mental health care and a commitment to the mental health and well-being of individuals with cystic fibrosis. Janice received the award at the North American Cystic Fibrosis Conference in Nashville, 2019.

Research topics: Different ways of coping and association with surviving. Long-time follow-up over 20 years.

Training and Networking Opportunities to date

Due to the cancellation of the conference in Lyon due to the Corona crisis, our plans for the conference have had to change. The focus will be on strengthening the network of European and International CF mental health care specialists. In order to promote and stimulate the exchange of information about CF in the mental health field, we hope to plan virtual meetings and relevant courses later in the year.

Currently the following events are being planned through digital means:

Annual General Meeting: The aim will be to meet with the representative 'Captains' from all over Europe as well as mental health representatives from the working group in the US. We will give an update of our ongoing projects and open up the meeting to discuss goals for next year.

Tomorrow's lounge: Title: We are screening…now what? Different treatment modalities in CF mental health (Lyon, 2020) Scheduled for June 2020

Meet the Experts session: Psychological impact of not being eligible for new treatments (Lyon 2020) Scheduled at another time in the year.

Evidence based pre conference workshop course:

PRACTICAL THERAPEUTIC MODALITIES TO MANAGE PSYCHOLOGICAL PROBLEMS, SLEEP AND PAIN IN ROUTINE CF CARE

This year we decided to combine the groups of the ECFS Mental Health Working Group and European Psychosocial Special Interest Group (EPSIG for a joint one-day course on the use of different therapy modalities in supporting CF patients to manage psychological problems, sleep and pain. The course is aimed at all members of the MDT including doctors, nurses, physiotherapists, dietitians, psychologists, social workers etc.

The course will introduce individuals to the concepts of Cognitive Behavioural Therapy (as recommended by the mental health guidelines) and Systemic and Family Focused

Therapy facilitated by two experienced psychologists; Lori Willem (BE) and Joanna Gardecki (DE). The emphasis is on the evidence for their effectiveness, the practical implications of using them in clinical settings, and a discussion about the next steps regarding further training and support. Participants will be given various case studies in groups in order to try and apply the concepts that have been discussed in a more practical way.

This course will take place online at a date to be announced.