

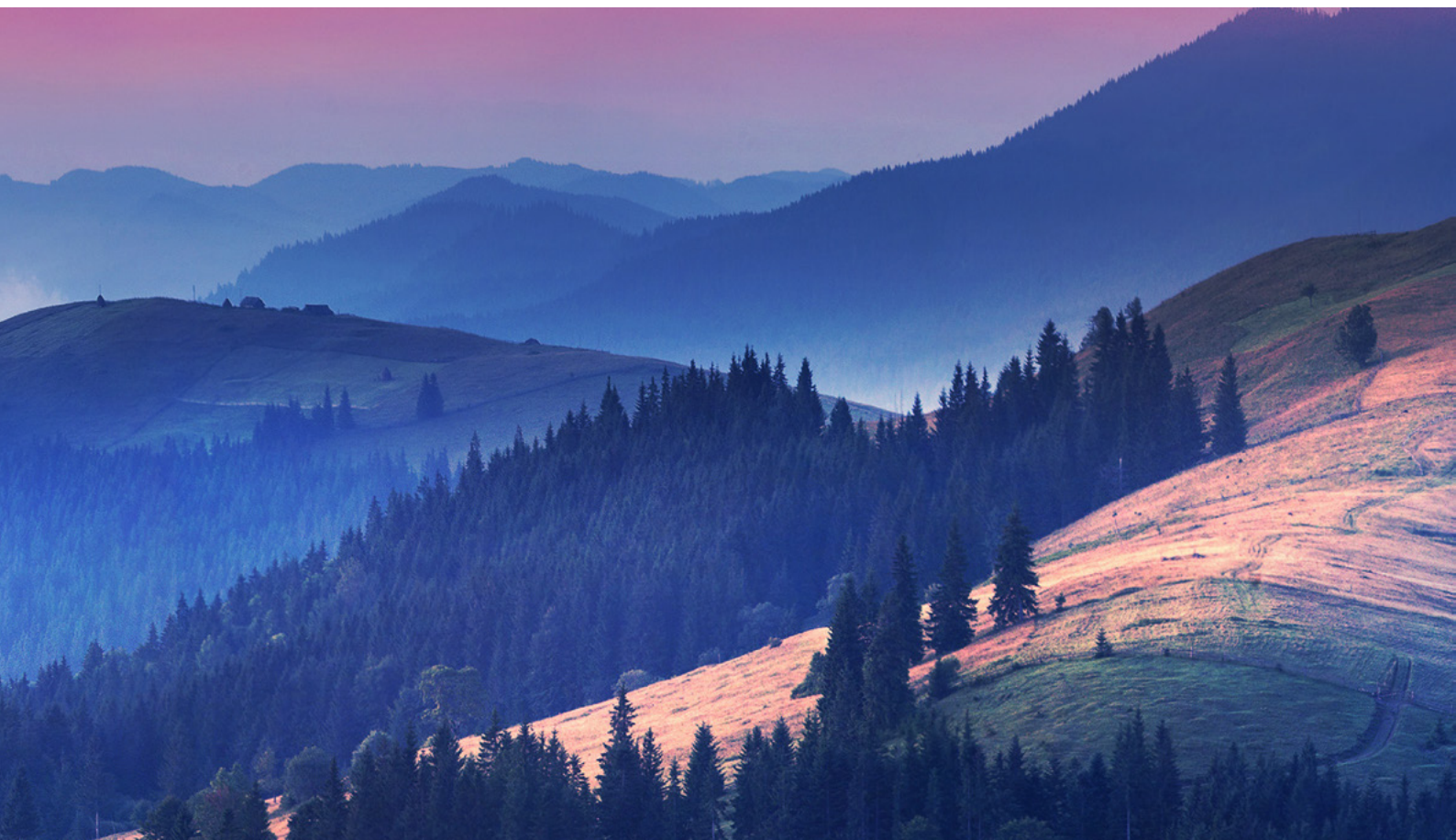


## **PARTNERSHIP WITHOUT BORDERS**

Hungary-Slovakia-Romania-Ukraine  
ENI CBC Programme 2014-2020



Project is  
co-financed  
by the  
European  
Union



# **WS 1 – CF EDUCATIONAL WORKSHOP 1** online

10-11, March 2021

## **PROGRAMME**

Language: english with translation to ukrainian and slovak



Hungary  
Slovakia  
Romania  
Ukraine

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### ORGANIZERS:



**RIMON**  
Charitable Foundation



Municipal non-profit enterprise  
«Ivano-Frankivsk regional  
children's clinical hospital  
of Ivano-Frankivsk regional council»

[www.odkl.if.ua](http://www.odkl.if.ua)

### ORGANIZING COMMITTEE:

Nataliya Pryanykova  
Katarína Štěpánková  
Monika Makian  
Nadyia Fomenko  
Halyna Makukh  
Táňa Hlivková  
Renáta Kováčová  
Larysa Voloshyna

# „MORE EDUCATION – LESS SUFFERING FOR CF PEOPLE“

Workshop is co-financed from HUSKROUA ENI CBC project HUSKROUA/1702/8.2/0008: SK UA CF CARE

„Transfer of know-how and creation of Cystic Fibrosis Centre to ensure better care for Cystic Fibrosis patients in Ivano-Frankivsk Region“

The Member States of the European Union have decided to link together their know-how, resources and destinies. Together, they have built a zone of stability, democracy and sustainable development whilst maintaining cultural diversity, tolerance and individual freedoms. The European Union is committed to sharing its achievements and its values with countries and peoples beyond its borders’

„The Hungary-Slovakia-Romania-Ukraine ENI CBC Programme 2014-2020 provides EU funding for sustainable development along the the border of Ukraine with Hungary, Slovakia and Romania, helps reducing differences in living standards and addressing common challenges across these borders.“

# PROGRAMME

## Wednesday, March, 10

### 09:00–10:00 Opening

- SHYYCHUK Oksana, IF Branch Office / HUSKROUA ENI CBC Programme 2014–2020
- PIDVERBETSKA Larisa, IF Regional State Administration, UKRAINE
- MELNYK Taras, IF Children's hospital, UKRAINE
- FOMENKO Nadyia, IF Children's Hospital, UKRAINE
- ŠTĚPÁNKOVÁ Katarína, chairwoman of Slovak CF Association, SLOVAKIA
- PRYANYKOVA Nataliya, Charitable Foundation Research Innovations in Medicine "RIMON"

**Project of cross-border cooperation with Ukraine ENI HUSKROUA – SK UA CF CARE** 20 min  
ŠTĚPÁNKOVÁ Katarina, Koshize, SLOVAKIA

**Actuality of creation the Cystic Fibrosis center in Ivano-Frankivsk** 10 min  
MAKIAN Monika, Ivano-Frankivsk, UKRAINE

### 10:00–10:10 Break

### 10:10–13:20 CF Patients Registry, Standards of CF care

Moderators: Makukh Halyna, Štěpánková Katarina

*Indications  
for sweat  
test*

**ECFS Patients Registry in Ukraine** 20 min  
MAKUKH Halyna, BOBER Lyudmyla, Lviv, UKRAINE

**Patients registry in Ivano-Frankivsk, as a part of SK UA CF CARE project - results 2020** 10 min  
FEDYNSKA Olha, IF, UKRAINE

**How to work in Tracker European CF Patients Registry software** 30 min  
KRASNYK Marko, Lviv, ECFSPR, UKRAINE

**Registry-based CF studies** 30 min  
JUNG Andreas, ECFSPR, Zurich, SWISS

**Q and A** 20 min

**European standards of CF care – CF Centres and MDT CF teams** 10 min  
LINDBLAT Anders., Goteborg, SWEDEN

**Current situation with Standards of care for CF patient in Ukraine** 40 min  
Speaker in question

**Management of CF children's care in CF Centers** 10 min  
JUNG Andreas, Zurich, SWISS

**Q and A** 20 min

### 13:20–14:00 Lunch

# PROGRAMME

## Wednesday, March, 10

### 14:00–15:10 **Adult CF care**

Moderators: Makukh Halyna, Bober Lyudmyla

<b>Features of CF in adult patients</b> YAKOVENKO Oleh, Lutsk, UKRAINE	20 min
<b>Case report</b> FEKETEOVA Anna., Košice, SLOVAKIA	10 min
<b>Our experiences with SIMEOX in adult CF patients</b> BÉREŠOVÁ Eva, ŠTEVULOVA Petra, Banská Bystrica, SLOVAKIA	30 min
<b>Q and A</b>	10 min

### 15:10–15:20 **Break**

### 15:20–17:30 **Importance of nutrition in CF**

Moderators: Bober Lyudmyla, Fomenko Nadiya

*Book  
about  
nutrition  
for CF*

<b>The value of nutritional status in life of CF patient</b> BOBER Lyudmyla, Lviv, UKRAINE	30 min
<b>Nutrition in CF children care</b> KURILLINA Tetyana, Kyiv, UKRAINE	30 min
<b>Principles of nutrition in patients with CF</b> NILSSON Mikael, Lund, SWEDEN	30 min
<b>Importance of nutrition in CF care</b> FEKETEOVÁ Anna, Košice, SLOVAKIA	10 min
<b>Nutritionist in CF team</b> NILSSON Mikael, Lund, SWEDEN	10 min
<b>Q and A</b>	20 min

# PROGRAMME

## Thursday, March, 11

### 09:00–11:40 **New therapies for CF and genetics**

Moderators: Makukh Halyna, Fomenko Nadiya

<b>Genetics of cystic fibrosis</b> MACEK Milan, Prague, CZECH REP.	60 min
<b>Clinical-Genetical Peculiarities of CF in the Precarpathian Region. Interrelations in Genotype-Phenotype System</b> FOMENKO Nadiya, Ivano-Frankivsk, UKRAINE	20 min
<b>Newborn screening in Ukraine</b> MAKUKH Halyna, Lviv, UKRAINE	10 min
<b>Towards curative treatment of CF</b> DŘEVÍNEK Pavel, Prague, CZECH REP.	50 min
<b>Q and A</b>	20 min

### 11:40–11:50 **Break**

### 11:50–14:20 **Diagnosis and treatment of lung disease in CF**

Moderators: Bober Lyudmyla, Makian Monika

<b>Diagnosis and treatment of lung disease of CF in Sweden</b> LINDBLAT Anders, Goteborg, SWEDEN	50 min
<b>Diagnosis and treatment of lung disease of CF in SLOVAKIA</b> FEKETEOVA Anna, Košice, SLOVAKIA	20 min
<b>Clinical cases of children with cystic fibrosis in Ivano-Frankivsk region</b> MAKIAN Monika, IF, UKRAINE	10 min
<b>Microbiology of CF lungs</b> DŘEVÍNEK Pavel, Prague, CZECH REP.	20 min
<b>CF and COVID-19</b> FEKETEOVA Anna, Košice, SLOVAKIA	20 min
<b>RESPILON – nanofibres for CF</b> MIKULIKOVA Eva, Respilon, CZECH REP.	10 min
<b>Q and A</b>	20 min

### 14:20–14:50 **Lunch**

# PROGRAMME

## Thursday, March, 11

### 14:50–16:00 ROCHE SYMPOSIUM

#### Patients with CF in Ukraine – roadmap from neonatal screening to adulthood

Moderator of symposium – Makukh Halyna

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<b>CF patient journey in Ukraine</b> MAKUKH Halyna	15 min
<b>Peculiarities of CF patient's management after neonatal screening</b> BOBER Lyudmyla	20 min
<b>Access to treatment for CF patient in Ukraine – what is done and next steps needed</b> GLYADELOVA Natalia	25 min
<b>Q and A</b>	10 min

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### 16:00–16:10 Break

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### 16:10–18:00 Importance of nutrition in CF II

Moderators: Makian Monika, Štěpánková Katarina

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<b>Principles of nutrition in patients with CF - PEG</b> NILSSON Mikael, Lund, SWEDEN	20 min
<b>PEG for CF</b> SERGEYENKO Anatoliy, Kyiv, UKRAINE	20 min
<b>Life with PEG</b> VOLOSHYNA Larysa, Kyiv, UKRAINE	10 min
<b>Q and A</b>	20 min
<b>Ukrainian CF Association – support and advocacy for CF patients in Ukraine</b> VOLOSHYNA Larysa, Kyiv, UKRAINE	20 min

#### Workshop closing:

- MAKIAN Monika
- ŠTĚPÁNKOVÁ Katarina
- PRYANYKOVA Nataliya



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АСОЦІАЦІЯ ДОПОМОГИ  
ХВОРИМ НА МУКОВІСЦИДОЗ»



ОРФАННІ ЗАХВОРЮВАННЯ УКРАЇНИ  
ГРОМАДСЬКА СПІЛКА



