Scientific and Practical Conference
CYSTIC FIBROSIS IN UKRAINE
with symposium “Orphan Diseases in Children and Adults”

12–14.10 2017
LVIV | UKRAINE

PROGRAM
DEAR !

We are pleased to invite you to take part in the Scientific and Practical Conference with international participation “CYSTIC FIBROSIS IN UKRAINE: STATUS AND PROSPECTS OF DIAGNOSTIC, TREATMENT AND SOCIAL ADAPTATION OF PATIENTS” with symposium “Orphan Diseases in Children and Adults”, which will take place on October 12-14, 2017 in Lviv, in conference halls of the hotel Taurus (5, Kn. Sviatoslava Sq).

REGISTRATION OF PARTICIPANTS OF THE CONFERENCE will be held on OCTOBER 12 AT 08:00-9:00 in hotel Taurus (2nd floor). For participation in the Conference it is necessary to pre-register by filling electronic registration form on the websites:

www.rimon.in.ua та www.cfu.com.ua

CONFERENCE OPENING CEREMONY – October 12, 2017.

ORGANIZER ADDRESS: 31a, M.Lysenko street, Lviv, 79008, Phone: (0322) 76-54-99 Phone/Fax: (0322) 75-38-44, 76-76-41, 75-23-04, E-mail: root@ihp.lviv.ua

CONFERENCE LANGUAGES: Ukrainian, English.

TECHNICAL SUPPORT: multimedia projector, simultaneous translation.
Dear friends and colleagues,

State Institution "The Institute of Hereditary Pathology of the National Academy of the Medical Sciences of Ukraine" traditionally holds scientific forums on diagnosing and treatment of congenital and hereditary diseases. In 2017, the conference is organized jointly with the Communal Establishment "Western Ukrainian Specialized Children’s Medical Center", which is collaborating in daily work to provide modern care to patients with orphan diseases. On behalf of the Organizing Committee, we congratulate you at the annual scientific and practical conference with international participation CYSTIC FIBROSIS IN UKRAINE: STATE AND PROSPECTS OF DIAGNOSTICS, TREATMENT AND SOCIAL ADAPTATION OF PATIENTS ON THE SYMPOSIUM ORPHAN DISEASES OF CHILDREN AND ADULTS to be held on October 12–14, 2017 in Lviv.

One of the most common and well-studied orphan nosologies is Cystic Fibrosis, with significant progress and experience to solve its problems in the world and in Ukraine, compared to other orphan diseases. Steps taken in solving the problem of DIAGNOSTICS, TREATMENT AND SOCIAL ADAPTATION OF PATIENTS with Cystic Fibrosis can be a model for other rare diseases. The international conference on Cystic Fibrosis in Lviv will be held for the second time and will be more focused on the experience of other countries and centers, problematic issues of treatment of adult patients with Cystic Fibrosis, and discussion of the state of this problem in different regions of Ukraine. A significant part of the conference will be the practical course of physiotherapy for Cystic Fibrosis.

We aim at attracting attention and increasing concern of practical doctors regarding the need for early detection of orphan pathology, the total frequency of which reaches 1 in 200 newborns. Orphan diseases, which are hereditary in most cases, are associated with the threat of perinatal losses, early childhood mortality and disability. The medical and social significance of early detection of orphan pathology deepen due to the fact that effective medication is currently available that can significantly improve the health and quality of life of these patients. Despite the fact that they occur comparatively rarely (orphan diseases), a patient with orphan pathology can come to see any doctor. Therefore, experts in the field of Cystic Fibrosis and other orphan diseases are invited to participate in the conference: geneticists, pediatricians, pulmonologists, general physicians, obstetrician-gynecologists, neonatologists, physiotherapists, gastroenterologists, nutritionists, psychologists. The participation of world-class experts will enable all conference participants to get acquainted with the latest developments in the field.

The conference is held at a time that requires the whole medical community to work hard every day on the tasks of reforming the health care system of the state. We are confident that the conference will provide an opportunity to meet researchers, scientists, practitioners, healthcare organizers, social workers, psychologists together to share up-to-date information, knowledge, experience, to establish contacts and collaboration to improve the quality of care for patients with orphan diseases.

We welcome guests from all over Ukraine and foreign guests in the city of Lviv, whith its beauty and history captivating tourists from all over the world. We hope that an interesting scientific program of the conference, along with communication with colleagues and acquaintance with a beautiful city, will stick in your memory for a long time.

We look forward to hearing from you. With best wishes,
Organizing Committee
## INTERNATIONAL EXPERTS

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<tr>
<th>Name</th>
<th>Topic</th>
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<tbody>
<tr>
<td><strong>ELIZABETH TULLIS</strong></td>
<td>CF CARE AND TREATMENT IN ADULTS</td>
<td>Theoretical and practical issues.</td>
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<tr>
<td>(Toronto, Canada)</td>
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<td>Elizabeth Tullis MD FRCP(C)</td>
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<td>Professor of Medicine</td>
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<td>Cystic Fibrosis Canada Chair in Adult CF Research</td>
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<td>University of Toronto</td>
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<td>Toronto, Canada</td>
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<tr>
<td><strong>CHRISTINE BEAR</strong></td>
<td>New drugs for CF treatment.</td>
<td>The practical results and expectation</td>
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<tr>
<td>(Toronto, Canada)</td>
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<td>Strategies for identifying those individuals with CF who may exhibit the best response to the new targeted therapies.</td>
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<td>Cystic Fibrosis Center, Co-Director. Senior Scientist Molecular Medicine, University of Toronto</td>
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<tr>
<td><strong>VALERIE WATERS</strong></td>
<td>Pathogenesis and treatment of infection process in CF.</td>
<td>The importance of epidemiology control</td>
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<tr>
<td>(Toronto, Canada)</td>
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<td>M.D., University of Toronto, Department of Pediatrics, Assistant Professor The Hospital for Sick Children</td>
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<td><strong>MILAN MACEK</strong></td>
<td>What we are doing for rare diseases: an overview of Czech activities and how this is relevant to CF</td>
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<tr>
<td>(Czech Republic)</td>
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<td>Head of Department of Biology and Medical Genetics, Charles University, Prague, Czech Republic</td>
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**CF CARE AND TREATMENT IN ADULTS**

Demonstration of specific cases of care and treatment for adult patients in Canada.
Discussion of prepared cases and questions by UA doctors.
The hope for CF patients – Registry data of CF adult patients in Canada.

**Progress in understanding of CFTR role and its impact on changes in treatment tactics**

**Pathogenesis and treatment of infection process in CF.**

The importance of epidemiology control
Antibiotic therapy in CF patients
Discussion of prepared cases and questions by UA doctors

**What we are doing for rare diseases: an overview of Czech activities and how this is relevant to CF.**
INTERNATIONAL EXPERTS

PAVEL DREVINEK
(Czech Republic)
EU standards for CF care. Guidelines matters. Detection of pathogenes in CF
head of Department of Medical Microbiology at the 2nd Faculty of Medicine, Charles University and Motol University Hospital in Prague, Czech Republic

HUGHES GAUCHEZ
(Paris, France)
The PHYSIOTHERAPY IN CF PATIENTS
Physiotherapist in MonDocteur, Paris

PETRA KOLCUNOVA
(Slovak republic)
PHYSIOTHERAPY IN CF PATIENTS. Sinus massage.
Expert consultant for physiotherapy in Cenrum LIBERTA

LUTZ NAEHRLICH
(Germany)
ECFPR data and importance for Ukraine
Director of the European Cystic Fibrosis Patient Registry (ECF-SPR)
PD, DR of Department of General Pediatrics and Pneumology University Hospital of Giessen and Marburg

DETECTION OF PATHOGENES IN CF

PHYSIOTHERAPY IN CF PATIENTS

PHYSIOTHERAPY IN CF PATIENTS
Sinus massage.

ECFPR data and importance for Ukraine.
Practical training of ecfstracker for CF registry.
INTERNATIONAL EXPERTS

MARK ROSENTHAL  
(UK)  
Why we do not do CF treatment?  
MD  
Consultant in Paediatric Respiratory Medicine, Royal Brompton Hospital, London  
• Consultant in Paediatric Respiratory Medicine, Portland Hospital, London  
• Consultant in Paediatric Respiratory Medicine, Cromwell Hospital, London  
Why we do not do CF treatment? Why are the doctor’s appointments not being performed?

ASHOK VELLODI  
(UK)  
GENETIC DIAGNOSTICS OF ORPHAN DISEASES  
Some aspects of lysosomal disease  
European Enjoyment Access Program «Genzyme»  
GENETIC DIAGNOSTICS OF ORPHAN DISEASES  
Some aspects of lysosomal disease.

KRZYSZTOF SZCZALUBA  
(Poland)  
GENETIC DIAGNOSTICS OF ORPHAN DISEASES  
Exome sequencing in the Diagnosis of Rare Diseases  
Dr n.med  
Department of Genetics, Medical University of Warsaw  
GENETIC DIAGNOSTICS OF ORPHAN DISEASES  
Exome sequencing in the Diagnosis of Rare Diseases
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<th>Time</th>
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<th>Hall 2</th>
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<td>08:00–09:00</td>
<td>REGISTRATION</td>
<td>Foyer</td>
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<tr>
<td>09:00–11:00</td>
<td>CF CARE AND TREATMENT IN ADULTS</td>
<td>PHYSIOTherapy in CF patients</td>
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<td>Theoretical and practical issues</td>
<td>Workshop for patients part 1</td>
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<td></td>
<td>Elizabeth Tullis, Canada</td>
<td>Mathilde Proffit, France</td>
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<td>Moderator: L.P. Sheyko, Ukraine</td>
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<td>11:00–11:30</td>
<td>COFFEE BREAK</td>
<td>PHYSIOTherapy in CF patients</td>
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<td>Banquet hall (2 floor)</td>
<td>Workshop for patients part 2</td>
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<td>Hughes Gauchez, France</td>
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<td>Mathilde Proffit, France</td>
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<td>11:30–13:30</td>
<td>DIAGNOSTICS AND TREATMENT OF CF: WHAT IS NEW?</td>
<td>PHYSIOTherapy in CF patients</td>
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<td>Satellite symposium</td>
<td>Workshop for patients part 2</td>
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<td>Moderator: H.V. Makukh, Ukraine</td>
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<td>13:30–14:30</td>
<td>LUNCH BREAK</td>
<td>PHYSIOTherapy in CF patients</td>
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<td>Banquet hall (2 floor)</td>
<td>Workshop for patients part 3</td>
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<td>Petra Kolcunova, Slovak Republic</td>
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<td>14:30–18:00</td>
<td>ACHIEVEMENTS OF CFCARE IN THE WORLD–PERSPECTIVE FOR UKRAINE</td>
<td>PHYSIOTherapy in CF patients</td>
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<td>Plenary lectures</td>
<td>Workshop for patients part 3</td>
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<td>Moderator: O.Z. Hnateyko, Ukraine</td>
<td>Petra Kolcunova, Slovak Republic</td>
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<td>The organization committee greetings</td>
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<td>18:00–20:00</td>
<td>WELCOME RECEPTION</td>
<td>Black&amp;White hall (1 floor)</td>
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| 08:30–11:00 | **CF TREATMENT: ANTIBIOTIC THERAPY IN CF PATIENTS**  
Workshop  
Valerie Waters, Canada  
Moderator: O.V. Lyha, Ukraine | **PHYSIOTHERAPY IN CF PATIENTS**  
Workshop for patients part 3  
Petra Kolcunova, Slovak Republic | **CONCEPT OF THE REGIONAL CENTER FOR ORPHAN DISEASES**  
Workmeeting  
Moderators: H.R. Akopyan, N.I. Synchuk, Ukraine | **PHYSIOTHERAPY IN CF PATIENTS**  
Workshop for patients part 3  
Petra Kolcunova, Slovak Republic |
| 11:00–11:30 | **COFFEE BREAK** Banquet hall (2 floor) | | | |
| 11:30–13:30 | **ALGORITHM FOR THE DIAGNOSIS OF ORPHAN PATHOLOGY IN MODERN MEDICAL PRACTICE**  
Satellite symposium  
Moderator: H.R. Akopyan, Ukraine | **PHYSIOTHERAPY IN CF PATIENTS**  
Sinusmassage  
Workshop for patients part 3  
Petra Kolcunova, Slovak Republic | **CF IN UKRAINE: STATE AND PERSPECTIVE**  
Presentation of abstract  
Moderator: N.M. Fomenko, Ukraine | | |
| 13:30–14:30 | **LUNCH BREAK** Banquet hall (2 floor) | | | |
| 14:30–16:30 | **USE OF SPECIALIZED INTERNET RESOURCES IN THE DIAGNOSTICS OF ORPHAN PATHOLOGIES. CONSIDERATION OF A SPECIFIC CASE OF RARE DISEASES**  
Reports  
Moderator: N.I. Synchuk, Ukraine | **WHY WE DON'T TREAT CF?**  
Moderator: N.V. Rohovyk, Ukraine | | |
| 16:30–17:00 | **COFFEE BREAK** Banquet hall (2 floor) | | | |
| 17:00–19:00 | **THE ROLE OF PATIENTS ORGANIZATION IN ESTABLISHING CARE OF RARE DISEASES**  
Moderator: O. Darmoryz, Ukraine | **DETECTION OF PATHOGENES IN CF**  
Bacteriology workshop Pawel Drevinek (Czech Republic)  
Moderator: D.O. Stepanskiy, Ukraine | | |
## CONFERENCE TIMETABLE

**Saturday, October, 14**

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<tr>
<th>Time</th>
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| 09:00–11:00 | **PROGRAMS OF THERAPEUTIC SUPPORT OF ORPHAN DISEASES IN UKRAINE AND IN THE WORLD. CF REGISTE**  
Plenary session  
Moderator: O.Y. Grechanina, Ukraine | **ASK THE EXPERT**  
Individual consultations for doctors and CF patients |
| 11:00–11:30 | **COFFEE BREAK**  
Banquet hall (2 floor) |  |
| 11:30–13:30 | **GENETIC DIAGNOSTICS OF ORPHAN DISEASES**  
Plenary session  
Moderator: L.A. Livshits, Ukraine | **PRACTICAL TEACHING OF ECFSTRACKER FOR CF REGISTRY**  
Training  
Lutz Naehrlich, Germany  
**ASK THE EXPERT**  
Individual consultations for doctors and CF patients |
| 13:30–14:00 | **SUMMARY OF WORK AND SIGNING OF THE RESOLUTION** |  |
### PROGRAM OF THE CONFERENCE

**08:00–09:00** Registration of participants (foyer)

**09:00–11:00** Theoretical and practical issues of CF care and treatment in adults. Cases demonstration: care and treatment in adults patients in Canada. Cases and questions discussion

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<td></td>
<td>Professor of Medicine Cystic Fibrosis Canada Chair, Adult</td>
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<td>CF Research University of Toronto</td>
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**11:00–11:30** Coffee break (banquet hall 2 floor)

**11:30–13:30** Satellite symposium

**11:30–13:30** Diagnostics and Treatment of CF – What is New?

**11:30–13:30** Moderators: H.Makukh, Ukraine, Hughes Gauchez, France

**11:30–11.45** New in the diagnosis and treatment of cystic fibrosis – what are the next challenges for Ukraine

**11:30–11.45** Interactive voting

**11:45–12:20** The key importance of physiotherapy at various stages of CF treatment

**11:45–12:20** Hughes Gauchez, Франція Physiotherapist in Mon Docteur

**12:20–12:50** The situation with the diagnosis and treatment of CF in various regions of Ukraine. Speeches by regional specialists

**12:20–12:50** Representatives of the CF centers from different regions of Ukraine

**12:50–13:10** Myths and reality in the medical accompaniment of cystic fibrosis

**12:50–13:10** L.Y. Bober, Ukraine

**13:10–13:30** Discussion

**13:30–14:30** Lunch break (banquet hall 2 floor)

**14:30–18:00** Plenary lectures

**14:30–15:00** Achievements of CFCare in the World – Perspective for Ukraine

**14:30–15:00** Moderator: O.Z. Hnateyko, Ukraine

**14:30–15:00** Progress in understanding of CFTR role and its impact on changes in treatment tactics

**14:30–15:00** Christine Bear, Canada

**14:30–15:00** Cystic Fibrosis Center, Co-Director. Senior Scientist Molecular Medicine, University of Toronto Professor

**15:00–15:30** Pathogenesis and treatment of infection process in CF. (The importance of epidemiology control)

**15:00–15:30** Valerie Waters, Canada

**15:00–15:30** University of Toronto, Department of Pediatrics, Assistant Professor The Hospital for Sick Children

**15:30–16:00** The hope for CF patients – Registry data of CF adult patients in Canada

**15:30–16:00** Elizabeth Tullis MD FRCP(C), Canada

**15:30–16:00** Director, Toronto Adult Cystic Fibrosis Clinic

**15:30–16:00** Head, Division of Respirology, St Michael's Hospital

**15:30–16:00** Professor of Medicine Cystic Fibrosis Canada Chair Adult CF Research University of Toronto

**16:00–16:30** EU standards for CF care. Guidelines matters

**16:00–16:30** Pawel Drevinek, Чехія

**16:00–16:30** Head of Department of Medical Microbiology at the 2nd Faculty of Medicine, Charles University and Motol University Hospital in Prague, Czech Republic
16:30–17:00  What can be achieved in Ukraine with a team of enthusiasts. An example of the Lviv region  
L. Bober, H. Makukh, Ukraine  
SI «Institute of Hereditary Pathology of NAMS of Ukraine»

17:00–18:00  The organization committee greetings  
OPENING CEREMONY  
O.Z. Hnateyko, Ukraine SI «Institute of Hereditary Pathology of NAMS OF UKRAINE»  
A.M. Synyuta, Ukraine Western Ukrainian Specialized Children’s Medical Centre  
I.V. Mykychak, Ukraine Department of Health Care of Lviv Regional State Administration  
K. Stepankova, Slovak republic, European CF Association (CF Europe)  
M. Romach, Canada SickKids Hospital  
H.E. Sellers, Canada The SickKids, Chair fund  
O.Darmoriz, Ukraine, Head of the Cystic fibrosis association "DZVIN"

18:00–20:00  Welcome reception  
Black&White Hall (1 floor)
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<th>Speakers</th>
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| 08:30–11:00 | **Workshop** ANTIBIOTIC THERAPY IN CF PATIENTS  
**Moderator:** O.V. Lyha, Ukraine | Valerie Waters, Canada University of Toronto, Department of Paediatrics, Infectious Diseases, Assistant Professor, The Hospital for Sick Children |
| 08:30–11:00 | **Theoretical and practical issues of antibiotic therapy in CF patients**  
**Discussion of the provided cases and questions** | N.V. Samonenko, N.O. Pychkur, Ukraine SI «Institute of Hereditary Pathology of NAMS of Ukraine»; Orphan diseases center, National children specialised hospital “ОHMATDYT” |
| 11:00–11:30 | **Coffee break (banquet hall 2 floor)**                                                      |                                              |
| 11:30–13:30 | **Satellite symposium**  
**ALGORITHM FOR THE DIAGNOSIS OF ORPHAN PATHOLOGY IN MODERN MEDICAL PRACTICE**  
**Moderator:** H.R. Akopyan, Ukraine | N.I. Synchuk, Ukraine Vinnytsya national medical University named after M. Pirogov  
O.V. Omelyanenko Lviv National Medical University named after D. Hałytsky  
O.P. Zdybska Rare (orphan) diseases center, Ukraine |
| 11:30–11:50 | **The role of family doctor and pediatrician in timely diagnosis of orphan diseases (lysosomal diseases of accumulation)** | O.V. Omelyanenko Lviv National Medical University named after D. Hałytsky  
O.P. Zdybska Rare (orphan) diseases center, Ukraine |
| 11:50–12:10 | **Manifestation of orphan pathology in the neonatal period: tactics of the neonatologist and geneticist** | G.O. Lezhenko, Ukraine Zaporizhzhya state medical University |
| 12:10–12:30 | **Selective screening of orphan pathology in conditions of pediatric hospital** | N.V. Olhovych, O.Y. Barynska, N.G. Gorovenko, Ukraine Orphan diseases center, National children specialised hospital “ОHMATDYT” |
| 12:30–12:50 | **Selective screening of hereditary diseases of metabolism. Experience and perspectives** | N.O. Zymak-Zakutnya , Ukraine Khmelnitsky Medical Genetic Center |
| 12:50–13:10 | **Tuberous Sclerosis: problems of diagnosis and perspectives of treatment** | N.O. Zymak-Zakutnya , Ukraine Khmelnitsky Medical Genetic Center |
| 13:30–14:30 | **Lunch break (banquet hall 2 floor)**                                                      |                                              |
| 14:30–16:30 | **Reports**  
**USE OF SPECIALIZED INTERNET RESOURCES IN THE DIAGNOSTICS OF ORPHAN PATHOLOGIES. CONSIDERATION OF A SPECIFIC CASE OF RARE DISEASES**  
**Moderator:** N.I. Synchuk, Ukraine | M. I. Dushar, H.R. Akopyan, Ukraine  
SI «Institute of Hereditary Pathology of NAMS of Ukraine»  
Anthony Pircosh, Poland Medical Faculty of the University of Rzeszow |
| 14:30–14:55 | **Use of Internet resource FACE2GENE in diagnosis orphan pathologies** | M. I. Dushar, H.R. Akopyan, Ukraine  
SI «Institute of Hereditary Pathology of NAMS of Ukraine»  
Anthony Pircosh, Poland Medical Faculty of the University of Rzeszow |
| 14:55–15:20 | **Use of Internet resource Clinical Eye Openers in diagnosis orphan pathologies** | L.S. Yevtushok, E.Y. Patzkun, Ukraine  
OMNI-net for children, Rivne Medical Genetic Center Transcarpathian medical genetic cabinet |
| 15:20–15:50 | **Use of Internet resource UTIS in the practice of predicting teratogenic effects on the fetus** | E. Y. Patzkun, Ukraine OMNI-net for children, Transcarpathian medical genetic cabinet |
| 15:50–16:00 | **Congenital fibrosis of the liver** | M.I. Dushar, SI «Institute of Hereditary Pathology of NAMS of Ukraine» |
| 16:00–16:10 | **Variant Hermansky-Pudlak syndrome associated with granulomatous colitis: diagnosis, clinical course and treatment** | L. Lozynska, A. Plawski, R. Lozynsky, N. Prokopchuk, B. Tretiak, M. Lozynska, Ukraine  
SI «Institute of Hereditary Pathology of NAMS of Ukraine» |
### PROGRAM OF THE CONFERENCE

<table>
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| 16:10–16:20   | Exclusive family case of Franceschetti syndrome in conjunction with anomalies of the central nervous system and larynx in the Prycarpathya region  
N. M. Fomenko, O.B. Synoverska, V.P. Semenyuk, U.R. Stashko, Ukraine  
Ivano-Frankivsk National Medical University |
| 16:20–16:30   | First results of genetic diagnosis of Wilson's disease  
H. Makukh, I. Haiboniuk, L. Piekuse,  
SI «Institute of Hereditary Pathology of NAMS of Ukraine», Ukraine  
Faculty of Medicine, Rigas Stradina Universitate, Latvia |
| 16:30–17:00   | Coffee break (banquet hall 2 floor)                                                          |
| 17:00–18:30   | THE ROLE OF PATIENTS ORGANIZATION IN ESTABLISHING CARE OF RARE DISEASES  
Moderator: O. Darmoryz, Ukraine |

#### Experience of Slovak-Ukraine cooperation on the problem of cystic fibrosis  
K. Stepankova, Slovak republic  
All-Ukrainian association of cystic fibrosis patients.  
L. Voloshyna, Ukraine  
Public Association "Orphan diseases of Ukraine"  
T. Kulesha, Ukraine  
Association for the care of patients with tuberous sclerosis  
I. Koncevych, Ukraine  
Association of rare diseases of Ukraine «Pulmonary hypertension» "PHURDA", The Fundation of "SistersDelila"  
O. Kulish, A. Guley, Ukraine  
NGO «Association of Disabled People - Patients with Gaucher disease  
O. Martynenko, Ukraine
## Program of the Conference

### 13:00–13:15
An algorithm for diagnosis of cystic fibrosis in Ukraine, provided that neonatal screening is restored
- **Z.I. Rossokha**, Ukraine

### 13:15–13:30
Data of cystic fibrosis registry as an instrument for improvement of CF diagnostic and care
- **H.V. Makukh**, Ukraine

### 13:30–14:30
Lunch break (banquet hall 2 floor)

### 14:30–16:30
WHY WE DON’T TREAT CF?

#### 14:30–14:50
Management of treatment behavior of CF patient
- **N.V. Rohovyk**, Ukraine
  - Western Ukrainian Specialized Children’s Medical Centre

#### 14:50–15:40
Why we do not do CF treatment?
- **Mark Rosenthal**, UK
  - Consultant in Paediatric Respiratory Medicine, Royal Brompton Hospital

#### 15:40–16:00
Why we do not do CF treatment? Psychological issues
- **K. Yavna**, Ukraine

### 16:00–16:30
Discussion

### 16:30–17:00
Coffee break (banquet hall 2 floor)

### 17:00–18:30
Bacteriology workshop
- **DETECTION OF PATHOGENES IN CF**
  - **Moderator**: D.O. Stepansky, Ukraine

### 17:00–17:40
Detection of pathogens in CF
- **Pawel Drevinek**, Чехія
  - Head of Department of Medical Microbiology at the 2nd Faculty of Medicine, Charles University and Motol University Hospital in Prague, Czech Republic
17:40–18:00 Biological properties of cultures P. aeruginosa sequestered in children with cystic fibrosis

D.O. Stepanskiy, Ukraine

18:00–18:20 Microbiological monitoring of selected cultures and their sensitivity to antibiotics in CF patients in dynamic (2013–2016)

L.S. Khimyak, O.V. Kusharska, Ukraine
Western Ukrainian Specialized Children's Medical Centre

18:20–18:30 Questions and discussion

08:30–11:00 Workshop for patients part 3
PHYSIOTHERAPY IN CF PATIENTS
Petra Kolcunova, Slovak Republic

11:00–11:30 Break

11:30–13:30 Workshop for patients part 3
Sinusmassage
PHYSIOTHERAPY IN CF PATIENTS
Petra Kolcunova, Slovak Republic

13:30–14:30 Break

14:30–16:30 Workshop for patients part 4
PHYSIOTHERAPY IN CF PATIENTS
Petra Kolcunova, Slovak Republic
### PROGRAM OF THE CONFERENCE

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<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker/Institution</th>
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<tr>
<td>09:00–11:00</td>
<td>Plenary session PROGRAMS OF THERAPEUTIC SUPPORT OF ORPHAN DISEASES IN</td>
<td><strong>O.Y. Grechanina, Ukraine</strong></td>
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<td></td>
<td>UKRAINE AND IN THE WORLD. CF REGISTRY</td>
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<tr>
<td>09:00–09:30</td>
<td>What are we doing for rare diseases: review of the Czech Republic</td>
<td><strong>Milan Macek Jr., Czech Republic</strong></td>
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<td>activities and how that related to the CF</td>
<td>Head of Department of Biology and Medical Genetics, Charles University, Prague</td>
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<td>09:30–10:00</td>
<td>Strategies for identifying those individuals with CF who may exhibit</td>
<td><strong>Christine Bear, Canada</strong></td>
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<td>the best response to the new targeted therapies</td>
<td>Cystic Fibrosis Center, Co-Director. Senior Scientist Molecular Medicine, University of Toronto Professor</td>
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<tr>
<td>10:00–10:30</td>
<td>How to join the ECFS-patient registry?</td>
<td><strong>Lutz Naehrlich, Germany</strong></td>
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<td>Director of the European Cystic Fibrosis Patient Registry (ECFSPR), Justus-Liebig-University Departement of Pediatrics</td>
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<tr>
<td>10:30–11:00</td>
<td>Psyconeurological hereditary diseases. Comorbidity. How to recognise</td>
<td><strong>O.Y. Grechanina, Ukraine</strong></td>
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<td>and treat</td>
<td>Director of the Rare (orphan) diseases center, Kharkiv</td>
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<td>11:00–11:30</td>
<td>Coffee break (banquet hall 2 floor)</td>
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<td>11:30–12:00</td>
<td>Some aspects of lysosomal diseases</td>
<td><strong>Ashok Vellodi, UK</strong></td>
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<td>European Enjoyment Access Program &quot;Genzyme&quot;</td>
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<td>12:00–12:30</td>
<td>Current state of molecular genetic research of orphan diseases:</td>
<td><strong>L. A. Livshits, Україна</strong></td>
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<td>experience and perspectives</td>
<td>Institute of Molecular Biology and Genetics of the National Academy of Sciences of Ukraine (Kyiv)</td>
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<tr>
<td>12:30–13:00</td>
<td>Exome sequencing in the Diagnosis of Rare Diseases</td>
<td><strong>Rafal Ploski, Krzysztof Szczaluba, Польша</strong></td>
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<td>Department of Genetics, Medical University of Warsaw</td>
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<td>13:00–13:30</td>
<td>Discussion</td>
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<td>13:30–14:00</td>
<td>SUMMARY OF WORK AND SIGNING OF THE RESOLUTION</td>
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Scientific and Practical Conference
CYSTIC FIBROSIS IN UKRAINE
with symposium
“Orphan Diseases in Children and Adults”

PROGRAM OF THE CONFERENCE

HALL 3

11:30–13:30 Training

11:30–13:30 Practical teaching of ecfstracker for CF registry

Lutz Naehrlich (Germany)
director of the European
Cystic Fibrosis Patient
Registry (ECFSPR).
Justus-Liebig-University
Departement of Pediatrics
Marko Krasnyk (Ukraine)

09:00–11:00 Individual consultations for doctors and CF patients
ASK THE EXPERT
Opportunity for doctors and patients to receive answers on particular clinical cases. Please note that the consultations will only provide in case to give an entire clinical information and attendance in the consultation the therapist who can provide all data about the patient. In the consultation could attend other specialists and conference participants. Format – workshop. Every single who interested to get a consultation have to submit a brief description to the organizing committee by e-mail:
cfu-conference17@cfu.com.ua

11:00–11:30 Coffee break (banquet hall 2 floor)

11:30–13:30 Individual consultations for doctors and CF patients
ASK THE EXPERT
Opportunity for doctors and patients to receive answers on particular clinical cases. Please note that the consultations will only provide in case to give an entire clinical information and attendance in the consultation the therapist who can provide all data about the patient. In the consultation could attend other specialists and conference participants. Format – workshop. Every single who interested to get a consultation have to submit a brief description to the organizing committee by e-mail:
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"H.E. Sellers Chair in Cystic Fibrosis at SickKids Hospital, Toronto, Canada
The SickKids H.E. Sellers Chair fund, has generously supported Dr. Valerie Waters and Dr. Christine Bear’s participation in the October 2017 Cystic Fibrosis in Ukraine Conference. The H.E. Sellers Chair in Cystic Fibrosis at SickKids was created to support research that can lead to a cure for cystic fibrosis and to improve the health and well-being of children with cystic fibrosis. SickKids was home to the discovery of the CF gene in 1989 by Dr. Lap-Chee Tsui, a previous chairholder."

The Ukraine Paediatric Fellowship Program began in 2013 and has been generously funded by members of the Ukrainian-Canadian community. The Program focuses on elevating paediatric medical training to build capacity and improve care for critically ill children in Ukraine. Physicians from Ukraine come to SickKids in Toronto, Canada to receive advanced training in specialized areas of paediatric medicine (neurosurgery, general surgery, oncology and more). In addition to this, advisory teams from SickKids travel to Ukraine to provide clinical consultation, education and training seminars, and further skill development.