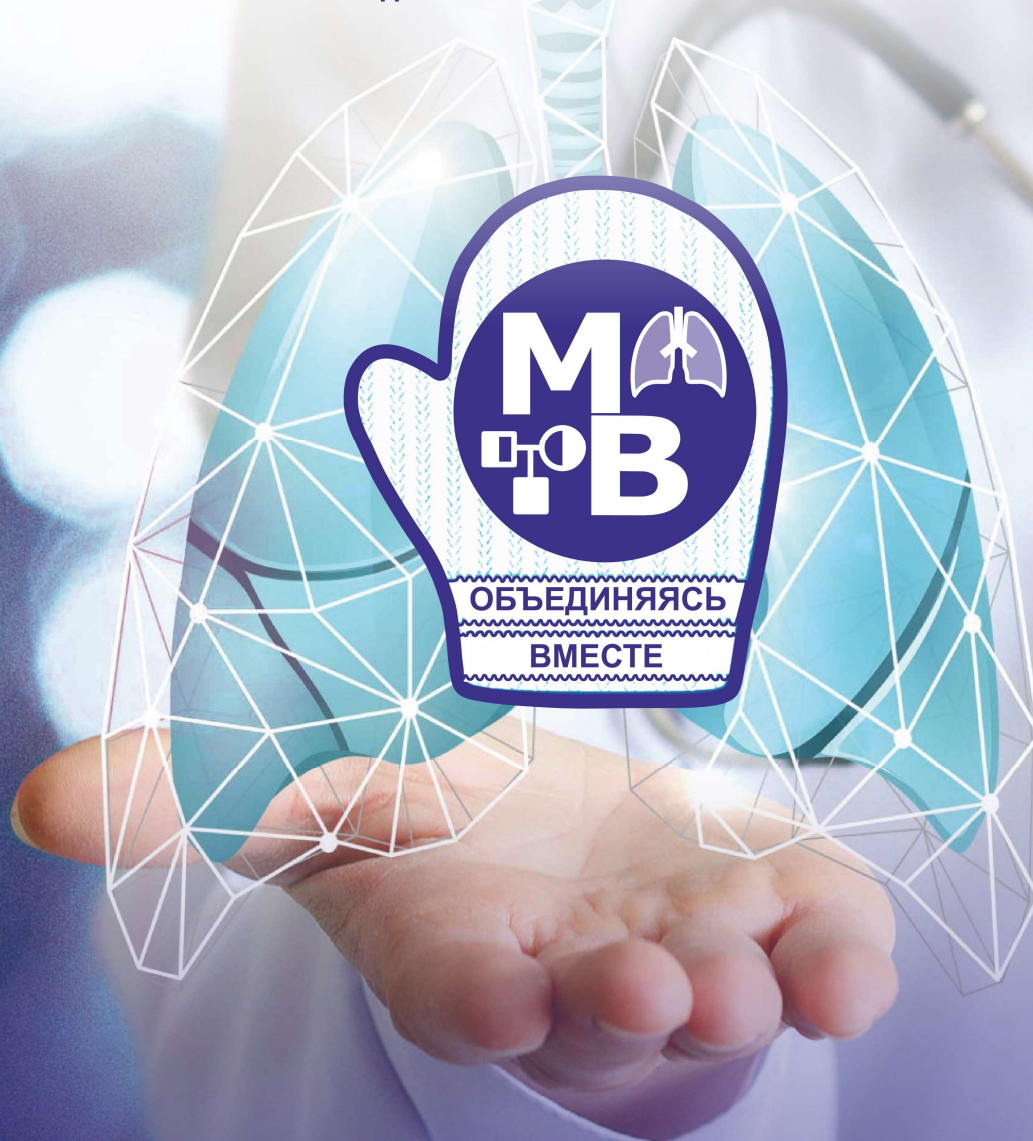


ALL-RUSSIAN PUBLIC ORGANIZATION
"ALL-RUSSIAN ASSOCIATION FOR CYSTIC FIBROSIS PATIENTS"
with the support of the Charitable Foundation "Ostrova"



PROGRAM

of the Second Forum of Medical and Public Organizations
"Let's unite efforts in the fight against cystic fibrosis"
with international participation

November 12-13, 2020

Online

November 12

CONFERENCE ROOM 1

09.00 a.m. – 09.40 a.m.	Forum Opening Session Moderator: Kutsev S.I.
09.00 a.m. – 09.10 a.m.	Welcome Speech Kutsev S.I. - Doctor of Medical Sciences, Corresponding Member of the Russian Academy of Sciences, Director of the Academician N.P. Bochkov Federal Medical Genetic Academic Center, Chief Specialist in Medical Genetics, Ministry of Health of Russia I.N. Kagramanyan - First Deputy Minister of Health of the Russian Federation N.V. Matveeva - Co-chairperson of the Organizing Committee, Vice-President of the All-Russian Association for Cystic Fibrosis Patients
09.10 a.m. – 09.25 a.m.	Lecture There is no future without history. 30 years of work of the Scientific and Clinical Department of Cystic Fibrosis of the Scientific Institution Research Centre of Medical Genetics named after N.P.Bochkov Kapranov N.I. (Moscow)
09.25 a.m. – 09.40 a.m.	Lecture Help for patients with orphan diseases in Russia – what's new? Kutsev S.I., Izhevskaya V.L. (Moscow)

Summing up the results of the year (November 2019 – November 2020)

Moderators: Kashirskaya N.Yu., Kondratyeva E.I.

Objectives of the section: Assessment of the results of solving the tasks set at the First Forum of Medical and Public Organizations "Let's unite efforts in the fight against cystic fibrosis" 2019.

	Summing up the results of the year (November 2019 – November 2020)
09.40 a.m. – 10.00 a.m.	- on the part of the medical community Kondratieva E.I. (Moscow)
10.00 a.m. – 10.20 a.m.	- on the part of parental organizations Myasnikova I.V. (10 min.), Dmitriyeva I.Yu. (10 min.) (Moscow)
10.20 a.m. – 10.30 a.m.	- on the part of the public chamber Kurbangaleeva E.Sh. (Moscow)
10:30 a.m. – 11:00 a.m.	Discussion, Q&A session
11:00 a.m. – 11:10 a.m.	Break

Session

"What has the COVID-19 pandemic brought us? Lessons learned"

Part 1

(National experience)

Moderators: Kondratyeva E.I., Kashirskaya N.Yu.

Objectives of the section: Consider the impact of the new coronavirus infection on the course of cystic fibrosis. Changes in the organization of care for CF patients in the new epidemiological situation.

11:10 a.m. – 11:30 a.m.	Lecture Cystic fibrosis and the new coronavirus infection. National experience (in children) Kondratyeva E. I. (Moscow)
11:30 a.m. –	Lecture

11:50 a.m.	Cystic fibrosis and the new coronavirus infection. National experience (in adults). Amelina E.L. (Moscow)
11:50 a.m. – 12:05 p.m.	Lecture Complex clinical and epidemiological situations and ways to solve them in a pandemic in real clinical practice Sherman V.D. (Moscow)
12:05 p.m. – 12:20 p.m.	Lecture What has changed in the organization of CF patients care in Russia? (as viewed by patients and their parents) Myasnikova I.V. (Moscow)
12:20 p.m. – 12:30 p.m.	Discussion, Q&A session
Session "What has the COVID-19 pandemic brought us? Lessons learned" Part 2 (International experience) Moderators: Kondratyeva E.I., Kashirskaya N.Yu.	
12:30 p.m. – 1:00 p.m.	Lecture Cystic Fibrosis and COVID-19 – International Project Rebecca Cosgriff (Great Britain)
1:00 p.m. – 1:20 p.m.	Lecture CF Foundation's work in a pandemic Bruce Marshall (USA)
1:20 p.m. – 1:45 p.m.	Lecture Trends and Analytical Issues in Register Data for 2020. Alexander Elbert (USA)
1:45 p.m. – 2:10 p.m.	Lecture What has changed in the organization of CF care in Europe? (as viewed by patients and their parents) Jacqueliën Noordhoek (Netherlands)
2:10 p.m. – 2:25 p.m.	Discussion, Q&A session
2:25 p.m. – 2:30 p.m.	BREAK
Session "Targeted therapy of cystic fibrosis" Moderators: Amelina E.L., Kondratyeva E.I.	
2:30 p.m. – 2:55 p.m.	Lecture Recent advances in targeted therapy (comparative characteristics of drugs, efficacy and safety, own experience of use) Kerem Eitan (Israel)
2:55 p.m. – 3:10 p.m.	Lecture Russian experience of using targeted drugs in the adult population. Hopes and disappointments Amelina E.L. (Moscow)
3:10 p.m. – 3:25 p.m.	Lecture Targeted drugs in children with CF in Russia. Own experience, prospects Kondratyeva E.I. (Moscow)
3:25 p.m. – 3:40 p.m.	Discussion, Q&A session

Session

"Nasal polyps relapses. Is there a solution?"

Moderators: Polyakov D.P., Shumkova G.L.

*Objectives of the section: Paranasal sinuses as the most important reservoir of infection of the bronchial tree.
Convincing the audience to monitor the upper airway from the moment CF is diagnosed.*

3:40 p.m. – 3:55 p.m.	Lecture Is it possible to avoid nasal polyps relapses? Recommendations of the otolaryngologist. Shumkova G.L. (Moscow)
3:55 p.m. – 4:15 p.m.	Lecture Why do many children with cystic fibrosis have difficulty in nasal breathing? What shall be done? Polyakov D.P. (Moscow)
4:15 p.m. – 4:25 p.m.	Lecture The importance of surgical treatment of chronic rhinosinusitis in adult patients with cystic fibrosis Sinkov E.V. (Moscow)
4:25 p.m. – 4:45 p.m.	Lecture When does a CF patient need an audiologist? Barilyak V.V. (Moscow)
4:45 p.m. – 5:00 p.m.	Discussion, Q&A session

November 12

CONFERENCE ROOM 2

Session

"Kinesitherapy for cystic fibrosis for patients of different ages"

Moderators: Simonova O.I., Tony Wolstenholme

Objectives of the section: Kinesitherapy as an integral part of the complex therapy of cystic fibrosis. Individual approach depending on the severity of lung disease, complications, patient preferences.

11:00 a.m. – 11:30 a.m.	Lecture What determines the choice of kinesitherapy method? Elizabeth Shepherd, Tracey Daniels (Great Britain)
11:30 a.m. – 12:15 p.m.	Workshop (with patient participation) Elizabeth Shepherd, Tracey Daniels (Great Britain)
12:15 p.m. – 12:30 p.m.	Lecture Equipment-assisted methods of kinesitherapy. There is a choice Tikhonova A.Yu., Simonova O.I. (Moscow)
12:30 p.m. – 12:50 p.m.	Lecture Cystic fibrosis and sports - target groups and amount of sport load Simonova O.I. (Moscow)

12:50 p.m. – 1:05 p.m.	Performance of the athlete and their parents Dance is my Life A.A. Tsvetkov, O.Yu. Tsvetkova (Yaroslavl)
1:05 p.m. – 1:20 p.m.	Performance of the athlete and their parents Cystic fibrosis and professional sports. Is that possible to combine them? N.V. Matveeva (Yaroslavl)
1:20 p.m. – 1:30 p.m.	Lecture Exercise therapy and breathing games as part of kinesitherapy S.A. Lomakin (Moscow)
1:30 p.m. – 14.00 p.m.	Discussion, Q&A session
2:00 p.m. – 2:20 p.m.	BREAK

Session

"Palliative care for children and young adults with cystic fibrosis at home"

Moderators: Savva N.N.

Objectives of the section: Clarify what palliative care means for patients with cystic fibrosis

2:20 p.m. – 2:40 p.m.	Lecture Being a "palliative child": what does it mean today in Russia? Polevichenko E.V. (Moscow)
2:40 p.m. – 3:05 p.m.	Lecture Palliative care in the United Kingdom Judy Maddison (Great Britain)
3:05 p.m. – 3:15 p.m.	Lecture Palliative care in Novosibirsk. Exchange of experience Koreneva G.V. (Novosibirsk)
3:15 p.m. – 3:30 p.m.	Lecture What is missing in the methodological support for the development of palliative care for children with cystic fibrosis? Savva N.N. (Moscow)
3:30 p.m. – 3:45 p.m.	Lecture Palliative care for young adults with cystic fibrosis at home: the experience of the Lighthouse Charity Foundation Romanenko E. V. (Moscow)
3:45 p.m. – 4:00 p.m.	Discussion, Q&A session

Meeting with a specialist: Disability Board of Review (DBR)

Moderators: Matveeva N.V., Kurbangaleeva E.Sh.

Objectives of the section: Acquaintance with new legislation in obtaining and extending disability, means of technical rehabilitation and the possibility of obtaining them.

4:00 p.m. – 4:20 p.m.	Lecture Work of DBR of the Yaroslavl region with CF patients, are there any specific features? Likhacheva I.V. (Yaroslavl)
4:20 p.m. – 4:40 p.m.	Lecture Difficulties with disabilities and means of rehabilitation in patients with cystic fibrosis in Russia.

	Kurbangaleeva E.Sh. (Moscow)
4:40 p.m. – 5:00 p.m.	Discussion, Q&A session

November 13

CONFERENCE ROOM 1

Session

"Proper nutrition - science or art?"

Moderators: Roslavl'tseva E.A., Jarosław Walkowiak

Objectives of the section: Present an individual approach to the selection of food, fortified products, the appointment of therapeutic mixtures depending on the nutritional status, the state of the gastrointestinal tract, the patient's preferences

10:00 a.m. – 10:25 a.m.	Lecture Modern assessment of nutritional status and body composition in children with cystic fibrosis Roslavl'tseva E.A., Sokolov I. (Moscow)
10:25 a.m. – 10:40 a.m.	Lecture Nutrition of patients with CF complicated by diabetes mellitus. Hila Elyshar Iron (Israel)
10:40 a.m. – 10:55 a.m.	Lecture Vitamins and trace elements. Advantages and disadvantages of multivitamin complexes. Maksim'ycheva T.Yu., Zhekaite E.K. (Moscow)
10:55 a.m. – 11:15 a.m.	Lecture Monitoring of vitamin content in a CF patient. Why is their deficit dangerous? The approaches to this problem in Poland. Jarosław Walkowiak (Poland)
11:15 a.m. – 11:30 a.m.	Discussion, Q&A session

Session

"The digestive system in cystic fibrosis"

Moderator: Roslavl'tseva E.A.

Objectives of the section: Demonstrate the clinical diversity of the gastrointestinal tract lesions in CF, controversial issues of diagnosis and treatment

11:30 a.m. – 11:45 a.m.	Lecture Distal intestinal obstruction syndrome remains a serious problem Anne Münck (France)
11:45 a.m. – 12:15 p.m.	Lecture The hepatobiliary system in cystic fibrosis: resolved and unresolved issues Carla Colombo (Italy)
12:15 p.m. – 12:35 p.m.	Lecture Effect of CFTR modulators on the digestive organs Anne Münck (France)
12:35 p.m. –	Lecture

12:50 p.m.	Damage to the pancreas and correction options – what's new? Asherova I.K. (Yaroslavl), Kashirskaya N.Yu. (Moscow)
12:50 p.m. – 1:00 p.m.	Discussion, Q&A session
1:00 p.m. — 1:30 p.m.	BREAK

Session

"Pharmaceutical products"

Moderators: Kondratyeva E.I., Kostyleva M.N.

Objectives of the section: Forced poly-pharmacy, adverse events, intolerance, antibacterial resistance, identification of a rational strategy

1:30 p.m. – 1:45 p.m.	Lecture Accumulated data on adverse drug events. Our actions Kostyleva M.N. (Moscow)
1:45 p.m. – 2:00 p.m.	Lecture Problems of antibacterial resistance from a clinician's point of view. Ways to overcome them Semykin S.Yu. (Moscow)
2:00 p.m. – 2:15 p.m.	Lecture Results of a multicenter study on the efficacy and safety of Tobramycin-Gobbi in cystic fibrosis E. I. Kondratyeva (Moscow)
2:15 p.m. – 2:30 p.m.	Lecture How to get an unregistered drug or the drug that is not currently available? Akhmadullin F.R. (Kazan)
2:30 p.m. – 3:00 p.m.	Discussion, Q&A session

Session

"Transplantation for cystic fibrosis"

Moderators: Amelina E.L., Simonova O.I.

Objectives of the section: The current state of the problem of lung and liver transplantation in the Russian Federation

3:00 p.m. – 3:20 p.m.	Lecture Indication of a lung transplant. What should the patient and their family prepare for? Ibavov I.U. (Moscow)
3:20 p.m. – 3:40 p.m.	Lecture Liver transplant. When conservative methods are exhausted Silina O.V. (Moscow)
3:40 p.m. – 4:00 p.m.	Lecture Therapeutic tactics in the terminal stage of liver disease Goryainova A.V. (Moscow)
4:00 p.m. – 4:10 p.m.	Discussion, Q&A session

4.10 p.m. – 4.30 p.m.

Discussion on the resolution. Forum Closing Session.

November 13

CONFERENCE ROOM 2

Session

"Organization of psychological and pedagogical assistance to a child with cystic fibrosis"

Moderators: Simonova O.I., Lazurenko S.B.

Section objectives: Psychologists will give advice to parents on maintaining a healthy psychological climate in the family, organization issues and treatment adherence.

10:00 a.m. – 10:30 a.m.	Lecture To be treated in order to live, not to live in order to be treated. Urszula Borawska-Kowalczyk. (Poland)
10:30 a.m. – 11:00 a.m.	Lecture Modern psychological and pedagogical technologies to support the family of a child with cystic fibrosis Sviridova T.V., Lazurenko S.B., Gerasimova A.M. (Moscow)
11:00 a.m. – 11:15 a.m.	Lecture How to organize your time to be on time for everything? Personal experience Prihodko O.V. (Moscow)
11:15 a.m. – 11:30 a.m.	Discussion, Q&A session
11:30 a.m. – 12:30 p.m.	BREAK

Session

"Hygiene is the basis for infection prevention"

Moderators: Nikonova V.S., Sherman V.D.

Objectives of the section: Outline the basic principles of infection control, prevention of an infectious process in the respiratory tract taking into account new epidemiological data

12:30 p.m. – 12:45 p.m.	Lecture Environmental hygiene of a child with cystic fibrosis. Nikonova V.S. (Moscow)
12:45 p.m. – 1:00 p.m.	Lecture Rules of conduct for outpatient and hospital visits. Hygiene of the nebulizer, breathing machines, vibration vests, etc. Sherman V.D. (Moscow)
1:00 p.m. – 1:15 p.m.	Lecture Nebulizer treatment in cystic fibrosis, issues and solutions Titova E.L. (Moscow)

1:15 p.m. – 1:30 p.m.	Discussion, Q&A session
1:30 p.m. – 2:00 p.m.	BREAK
Session "Joint meeting of foundations and public organizations" Moderators: Pylaeva O.N. <i>Session purpose: Organization of a home hospitalization unit. Informing of the propositions for changing the roadmap for improving the quality of medical care for patients with cystic fibrosis, which were sent to the Ministry of Health of the Russian Federation.</i>	
2:00 p.m. – 2:15 p.m.	Lecture Antibacterial therapy at home is the only correct solution in a pandemic. Our improvements Amelina E.L. (Moscow)
2:15 p.m. – 2:55 p.m.	Lecture Community care organization for CF patients in the United Kingdom Judy Maddison (Great Britain)
2:55 p.m. – 3:10 p.m.	Lecture Experience in organizing i/v therapy at home in Novosibirsk Koreneva G.V. (Novosibirsk)
3:10 p.m. – 3:25 p.m.	Discussion
3:25 p.m. - 3:40 p.m.	Lecture Review of current propositions for changing the roadmap for improving the quality of medical care for patients with cystic fibrosis. O.N. Pylaeva (St. Petersburg)
3:40 p.m. - 4:00 p.m.	Discussion

November 13

<u>CONFERENCE ROOM 3</u>	
Symposium supported by Sanofi (for doctors only) "News from the North American Cystic Fibrosis Conference" Moderator: E. I. Kondratyeva	
11:30 a.m. – 11:45 a.m.	Lecture New approaches to the treatment of cystic fibrosis patients E. I. Kondratyeva (Moscow)
11:45 a.m. – 12:00 p.m.	Lecture Management of pulmonary exacerbations. Chronic and acute processes E.L. Amelina (Moscow)

12:00 p.m. – 12:15 p.m.	Lecture Gastrointestinal disorders. Unresolved issues. N.Yu. Kashirskaya (Moscow)
12:15 p.m. – 12:30 p.m.	Q&A session.
<p>Meeting with a professor "Cystic fibrosis in Russia through the eyes of a foreign expert" (for doctors only)</p> <p>Moderator: Kashirskaya N.Yu., Simonova O.I. <i>Objectives of the section: Exchange of experience in consulting work in Russia</i></p>	
1:00 p.m. – 1:30 p.m.	Meeting with a Professor - Eitan Kerem (Israel)
1:30 p.m. – 2:00 p.m.	Discussion, Q&A session

OFFICIAL EVENT OPERATORS:



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