

Main organizers

MATIO – Fundacja Pomocy Rodzinom i Chorym na Mukowiscydozę, PL
Slovenská Asociácia Cystickej Fibrózy, SK

Partners

Klub nemocných cystickou fibrozou, CZ
Országos Cisztás Fibrózis Egyesület, HU
EuroCareCF
CF Europe



FUNDACJA POMOCY
RODZINOM I CHORYM
NA MUKOWISCYDOŻĘ



SLOVENSKÁ ASOCIÁCIA
CYSTICKEJ
FIBRÓZY



Registration

20.11.2008 (17.00–19.00) Hotel CRACOVIA
21.11.2008 (7.00–8.30) Hotel CRACOVIA
22.11.2008 (8.00–10.00) Office of City Krakow, Plac Wszystkich Świętych 3-4

Contacts

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Under patronage of
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Polish Ministry of Health
Ireneusz RAŚ
Deputy

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Marshal of the Malopolskie Voivodeship
Head of the regional selfgovernment

Małgorzata RADWAN-BALLADA
Chairman of the Office of City Krakow



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3rd EUROPEAN CF DAY

November 21, 2008

20–22, November 2008
Salt Mine Wieliczka – Kraków
City of Krakow

www.v4-cf.eu

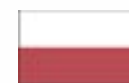
PROGRAMME

CONFERENCE

V4-CF

20–22 November 2008
Kraków, Wieliczka

**Better?
Why not!
Together
we could more**



PROGRAMME

THURSDAY (November 20, 2008)

19.00–21.00 Welcome reception
Hotel CRACOVIA

FRIDAY (November 21, 2008)

Salt Mine Wieliczka

8.30 Departure to WIELICZKA

9.30 Sightseeing in Salt mine

11.30 Coffee break

12.00 Opening

CICHY Wojciech

WÓJTOWICZ Paweł, Polish CF Foundation MATIO

ŠTĚPÁNKOVÁ Katarína, Slovak CF Association

RAŚ Ireneusz, deputy

SONIK Bogusław, eurodeputy

Polish government

Representative of Salt Mine

NAWARA Marek, Head of regional government

12.35 3th European CF Day

DeRIJCKE Karleen, CF Europe

12.45 Lunch

Standards of care for patients with CF: A European consensus (13.45–15.45)

Colombo C., Cichy W., Dřevínek P., Kačaba I.

13.45 EuroCareCF Workpackage 1. Standards of care for patients with CF: A European consensus – ECFS document

COLOMBO Carla, EuroCareCF

14.00 Implementation of ECFS document in Poland

POGORZELSKI Andrzej, POLAND

14.30 Implementation of ECFS document in Slovakia

OROSOVÁ Jaroslava, ŠTĚPÁNKOVÁ Katarína, SLOVAKIA

15.00 Inhaled antibiotics in Cystic Fibrosis

SANDS Dorota, POLAND

15.30 Discussion

15.45 Coffee break

Standards of care for patients with CF: A European consensus (16.00–17.45)

Colombo C., Cichy W., Dřevínek P., Kačaba I.

16.00 Inhaled antibiotic therapy in Cystic Fibrosis

MAZUREK Henryk, POLAND

16.15 Implementation of ECFS document in Czech rep.

DŘEVÍNEK Pavel, SKALICKÁ Veronika, CZECH REP.

16.45 Implementation of ECFS document in Hungary – CF care in Hungary

UJHELYI Rita, HOLICS Klara, HUNGARY

17.15 Social Welfare Services for People with Cystic Fibrosis in Hungary

KUTSAN Orsolya, HUNGARY

17.30 Discussion

18.00 Departure to Krakow

19.00 Dinner

SATURDAY (November 22, 2008)

Office of City Krakow, Plac Wszystkich Świętych 3-4

Genetics of Cystic Fibrosis (9.00–10.45)

Zielenski J., Sands D., Mosse N.

9.00 Recent Advances in the Genetics of Cystic Fibrosis

ZIELENSKI Julian, CANADA

9.45 Cystic Fibrosis Molecular Diagnosis – The Principles

WERTHEIM Katarzyna, Czerna Kamila, Norek Aleksandra, Sobczyńska-Tomaszewska Agnieszka, POLAND

10.00 CFTR-related diseases rarely associated with defect in CFTR gene

NOREK Aleksandra, Sobczyńska-Tomaszewska Agnieszka, Czerna Kamila, Wertheim Katarzyna, Bal Jerzy, POLAND

10.15 Molecular diagnosis of Cystic Fibrosis in Belarus

MOSSE Nataliya, MOSSE Konstantin, BELARUS

10.30 Discussion

10.45 Coffee break

Newborn screening of CF (11.15–12.30)

Sands D., Skalická V.

11.15 Organisation and methods of CF NBS in Poland (IRT test),

OŁTARZEWSKI Mariusz, POLAND

11.30 Molecular diagnosis of CFTR gene in neonatal screening for cystic fibrosis

SOBCZYŃSKA-TOMASZEWSKA A., POLAND

11.40 Clinical follow-up of diagnosed infants.

SANDS Dorota, POLAND

12.00 Management of CF children 0-3 years

SKALICKÁ Veronika, CZECH R.

12.15 Discussion

12.30 Coffee break

CF treatment and care (12.45–14.45)

Colombo C., Dřevínek P., Gauchez H.

12.45 Adult CF Care

KÁRÁSZ Bernadett, HUNGARY

13.00 CFRLD – CF Related Liver Disease

COLOMBO Carla, ITALY

13.20 Burkholderia cepacia complex and CF

DŘEVÍNEK Pavel, CZECH REP.

13.35 Importance of daily chest physiotherapy for CF patients

GAUCHEZ Hugues, FRANCE

14.05 Autogenic Drainage – film

BORKA Péter, HUNGARY

14.15 Adult with Cystic Fibrosis

SKORUPA Wojciech, POLAND

14.30 Discussion

14.45 Lunch

CF physiotherapy and quality of life (15.45–17.10)

Nobili R., Krzyzanowski M., Znotina I.

15.45 Survival of Cystic Fibrosis patients in Latvia in regard to care and treatment

ZNOTINA Inese, SVABE Vija, TEIBE Uldis, LATVIA

16.00 Medical and social aspects of Cystic Fibrosis

HORLENKO Olesya M., Yankovska Andriyana O., Kishko Nelli U., Packun Erica U., UKRAINE

16.15 CFQ-R cultural adaptation process: a base for quality of life understanding and comparison across the world

NOBILI Rita, ITALY

16.30 “LIFE CLUB CF”

KRZYŻANOWSKI Mikołaj, CICHY Wojciech, MIKOS Marcin, WÓJTOWICZ Paweł, POLAND

16.45 New Therapies – new chance for CF patients

CZERSKA Kamila, POLAND

17.00 Discussion

17.10 Coffee break

General assembly (17.20–18.00)

Wójtowicz P., Štěpánková K., Kačaba I.

17.20 CF Europe

DeRIJCKE Karleen, CF Europe

17.35 V4 CF Declaration about Standards of care

Kačaba I., Wójtowicz P., Štěpánková K.

17.50 Discussion

18.00 Closing