

**2009 Balkans Regional Cystic Fibrosis  
Conference  
Skopje, Macedonia  
April 17th and 18th**

*Hosted by Cystic Fibrosis Worldwide working in collaboration with CF  
Macedonia*

**Medical Seminar**

**17 April 2009  
09:00 - 09:30**

**Day I  
Conference opens, Welcome  
Prof. Efremov**

09:30 – 10:00

**Cystic Fibrosis, From Gene to Disease**  
*Dr. Harry Heijerman, Pulmonologist, CFW Medical Advisor*

10:30 – 11:00

**Early Lung Disease, Diagnostics and Monitoring**  
*Dr. Ian Balfour-Lynn, Royal Brompton Hospital, London UK*

Coffee Break

11:30 – 12:00

**Prevention of Chronic Infection with PA**  
*Dr. Steven Conway, Leeds Regional Adult CF Unit, UK*

12:00 – 12:30

**Treatment of Chronic Pseudomonas Infections**  
*Dr. Harry Heijerman, Pulmonologist, CFW Medical Advisor*

Lunch

14:00 – 14:30

**Diagnosis and Treatment of Pancreatic Insufficiency**  
*Dr. Anne Munck, Gastroenterologist, ECFS Board of Directors*

14:30 – 15:00

**European Standards of Care, CF Centre Standards**  
*Su Madge, CF Nurse, ECFS and ING/CF*

Coffee Break

15:30 – 16:00

**Treatment of Pulmonary Exacerbations**  
*Dr. Ian Balfour-Lynn, Royal Brompton Hospital, London UK*

16:00 – 16:30

**Inhaled Therapies (no antibiotics)**  
*Dr. Steven Conway, Leeds Regional Adult CF Unit, UK*

16:30 – 17:00

**Q & A**

**Allied Health Professional Workshop**

9:30 – 10:30

**CF Nursing**  
*Su Madge, CF Nurse, ECFS and ING/CF*

10:30 – 12:00

**Nutrition "Nutrition and Enzymes: That's Where It Starts!"**  
*Alison Morton, Dietician at Leeds Regional Adult CF Unit, UK, member of  
ECFNG and UK Dieticians*

14:30 – 17:00

**Physiotherapy; Inhalation therapy, airway clearance and  
physical exercise**  
*Louise Lannefors, Physiotherapist, Lund University Hospital, Sweden,  
IPG-CF*

## CFW Lay Seminar

|               |   |
|---------------|---|
| 8:30 - 10:00  | Registration  |
| 10:00 – 10:15 | Welcome and Introduction to Cystic Fibrosis Worldwide<br><i>Christine Noke, Executive Director CFW</i>  |
| 10:15 – 11:00 | Cystic Fibrosis Disease and Treatment<br><i>DR Fustic, Macedonia CF Centre Director</i>   |
| Coffee Break  |   |
| 11:30 - 12:30 | Physiotherapy; An important part of the treatment package<br><i>Louise Lannefors, Physiotherapist, Lund University Hospital, Sweden, IPG-CF</i>   |
| Lunch         |   |
| 13:30 - 14:00 | Nutrition "Nutrition and Enzymes: That's Where It Starts!"<br><i>Alison Morton, Dietician at Leeds Regional Adult CF Unit, UK, member of ECFNG and UK Dieticians</i>  |
| 14:00 – 15:00 | Living with CF<br><i>*our panel of experts*</i><br><br>"Adult with CF" What can we achieve?<br><i>CF Adult and student, Macedonia</i><br><br>"Being a CF Parent" Where are the answers?<br><i>Mother of PT, Macedonia</i><br><br>"Fighting back" Volunteer and make a difference!<br><i>Marc Basteinsen, CFW Supporter and CF Adult</i> |
| 15:00 – 15:30 | Q & A   |
| Break         |   |
| 16:00 – 16:30 | Standards of Care, European Consensus Review<br>Developing CF Centre's, what will work for your country?<br><i>Su Madge, CF Nurse, ECFS and ING/CF</i>  |
| 16:30 – 17:00 | Q & A   |
| 17:00         | Closing Remarks<br><i>Christine Noke, MB, Executive Director, CF Worldwide</i>  |

## Medical Seminar

|                      |   |
|----------------------|---|
| <b>18 April 2009</b> | <b>Day II</b>   |
| 09.30 – 10.00        | Nutrition from Infancy to Adulthood<br><i>Dr. Anne Munck, Gastroenterologist, ECFS Board of Directors</i> |
| 10.30 - 11.00        | New Therapies<br><i>Dr. Steven Conway, Leeds Regional Adult CF Unit, UK</i>                               |
| Coffee Break         |   |
| 11.30 – 12.00        | Cystic Fibrosis Related Diabetes  |

|                               |  |
|-------------------------------|--|
| 12.00 – 12.30                 | <i>Dr. Harry Heijerman, Pulmonologist, CFW Medical Advisor</i><br>Physiotherapy; Maintain airways aerated and the body fit<br><i>Louise Lannefors, Physiotherapist, Lund University Hospital, Sweden, IPG-CF</i> |
| Lunch                         |  |
| 14.00 – 14.30                 | Liver disease, DIOS and other GI manifestations<br><i>Dr. Anne Munck, Gastroenterologist, ECFS Board of Directors</i>  |
| 14.30 – 15.00                 | ABPA, Haemoptysis, Pneumothorax, and other Pulmonary complications<br><i>Dr. Ian Balfour-Lynn, Royal Brompton Hospital, London UK</i>  |
| Coffee Break<br>15.30 – 16.00 | Home IV treatment<br><i>Dr. Harry Heijerman, Pulmonologist, CFW Medical Advisor</i>  |
| 16.00 – 16.30                 | Centre care<br><i>Sue Madge, CF Nurse, ING/CF</i>  |
| 16.30 - 17.00                 | Q & A  |

### Allied Health Professional Workshop

|               |  |
|---------------|--|
| 10:30 – 11:30 | CF Nursing<br><i>Su Madge, CF Nurse, ING/CF</i>  |
| 11:30 – 12:30 | Nutritional Challenges<br><i>Alison Morton, Dietician at Leeds Regional Adult CF Unit, UK, member of ECFNG and UK Dieticians</i>             |
| 13:30 – 15:00 | Physiotherapy; aspects in different ages and adherence<br><i>Louise Lannefors, Physiotherapist, Lund University Hospital, Sweden, IPG-CF</i> |

### CFW Lay Seminar

|               |  |
|---------------|--|
| 9:30 – 10:00  | Cystic Fibrosis, Gene to Disease<br>Prof. Efremov  |
| 10:00 – 11:00 | Capacity Building, Organizational Development <ul style="list-style-type: none"> <li>• Developing By-Laws</li> <li>• Developing a Board of Directors</li> </ul> <i>Sharon M. Lund, M.S., Ph.D, University of Minnesota, Research Coordinator</i> |
| 10:30 – 11:00 | Developing an Organizational Strategic Plan <ul style="list-style-type: none"> <li>• Determine Needs</li> <li>• Develop programs</li> <li>• Set Goals and Timelines</li> </ul> <i>Christine Noke, MBA, Executive Director, CF Worldwide</i>      |
| Break         |  |
| 11:30 – 12:00 | Developing an Organizational Strategic Plan <ul style="list-style-type: none"> <li>• Determine Needs</li> <li>• Develop programs</li> <li>• Set Goals and Timelines</li> </ul> <i>Christine Noke, MBA, Executive Director, CF Worldwide</i>      |
| 12:00 – 12:30 | Latest Treatment and Research  |

*Macedonia based CF Doctor,*

Lunch

| Capacity Building, *Raising funds to support the mission!*

14:00 – 14:30

**Developing a Fundraising Plan**

*Marc Basteinsen, CFW Supporter and CF Adult*

14:30 – 15:00

**Events, *From Start to Finish!***

*Christine Noke, MBA, Executive Director CFW*

Break

15:30 – 16:00

**Grant Writing, *The Basics to Success!***

16:00 – 16:30

**Proposal to Budget, *What you need to know***

*Sharon M. Lund, M.S., Ph.D, University of Minnesota, Research Coordinator*

16:30 – 17:00

**Lobbying Governments, *Resources and Methods***

*Snezana Bojincin, CF Macedonia*

17:15 – 17:45

**Q & A**

**Ask the CFW Educational Team**

*Dr. Harry Heijerman, Pulmonologist, CFW Medical Advisor*

*Christine Noke, MBA Executive Director CFW*

*Alison Morton, Dietician at Leeds Regional Adult CF Unit, UK, member of ECFNG and UK Dieticians*

*Louise Lannefors, Physiotherapist, IPG-CF*

*Sue Madge, CF Nurse, ING/CF*

*Marc Basteinsen, CFW fundraiser and CF Adult*

*Dr. Anne Munck, Gastroenterologist, ECFS Board of Directors*

*Dr. Steven Conway, Leeds Regional Adult CF Unit,*

*Sharon M. Lund, M.S., Ph.D, University of Minnesota, Research Coordinator*

*Dr. Ian Balfour-Lynn, Royal Brompton Hospital, London*

17:45

**Conference Closing**

*Christine Noke, Executive Director CFW*

*Snezana Bojincin, CF Macedonia*

*Dr. Fustic, Director of Macedonia CF Centre*