

This page contains some more details of CHI's work in Ukraine in 2011. It provides extra details to [the main page on the project](#), and is not intended to be read on its own.

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## **Appeal from DZVIN, June 2009**

My colleagues in West Ukrainian CF association DZVIN are interested that EuroCareCF has funds available for training grants and some resources.

“DZVIN” is an organization of Cystic Fibrosis patients and their parents. Charitable Foundation “DZVIN” is a non-profit organization, the main goal is to help the Cystic Fibrosis -sick children, to support effective diagnosis, treatment and rehabilitation programmes for cystic fibrosis sick children, to support new medical projects and programmes of effective CF diagnostics and treatment. It was created to: consolidate parents, doctors, scientists, public efforts with cystic fibrosis problems-the most spreading out genetical disease; change the information; fulfill into the life common projects of modern world-level medical achievements to help sick children with such heritage pathology.

We are looking for support and we are very interested in receiving funds for realization of our projects.

1. To organize CF National Ukrainian association. With Solvay to support three leaders (From Lviv – Olha Hinka (DZVIN). From Kiev – President Vira Novak. From Kharkov – Olesia Bocura) were very close to organize CF National Ukrainian association in 2003- 2004. But it has not yet been achieved.
2. Attending of CF experts from Europe CF departments in Ukraine to share their expertise and support the local association in any way possible.
3. We are eager to organize a Ukrainian national CF meeting (for the first time) in our city Lviv. We would be able to invite all the interested in CF people from Ukraine.
4. To employ one person in DZVIN to promote the activity of organization (answer the e-mail, restart web-page, applying with project) .
5. To get training for specialist in CF adult treatment and for CF psychologist.
6. For somebody from European parents association to meet CF parents from Ukraine and explain how their role is important.
7. Receiving reference strains for the identification of CF microbiological pathogens.

President of West Ukrainian CF association DZVIN *Oksana Darmoriz*

Scientific Coordinator of West Ukrainian CF association DZVIN *Halyna Makukh*

## Visits to RBH, February and July, 2011

### Program

UK programme for Dr Nataliya Rohovyk (NR) and Kateryna Yavna, Psychologist(KY)  
20-27 February 2011

Date/ Time	Event	With whom	Remarks
<b>Sunday</b> 20 <sup>th</sup> February			
	Arrive Heathrow Airport T1 on Austrian Airlines flt 455 at 1840	TW	TW will meet and escort to RBH hostel.
<b>Monday</b> 21st February			

0900-1230	Introduction to RBH +CF care in UK	Dr Rosenthal in Dr Rosenthal's office (tbc)	Meet Dr Rosenthal in Reception at 0900
1230-1315	Both -CF clinic multidisciplinary meeting	Dr Rosenthal	In Morphology Museum
1330-1630	Both – CF Clinic	Dr Rosenthal	In Paediatrics Out Patients
1630-1900	London sightseeing	TW	
<b>Tuesday</b> 22 <sup>nd</sup> February			
0900-1600	KY with psychologist		Fulham Road building
0900-1100	NR – Asthma Clinic	Prof Andy Bush	Fulham Road building
1130-1300	NR – With adult physios	Vicky Robinson	Fulham Road building
1400 – 1500	NR – specialist nurse role	Jacque Francis	Rose Ward
1500- 1600	Difficult Asthma meeting	Prof Andy Bush and Dr Rosenthal	Surgical seminar room, 4 <sup>th</sup> floor
<b>Wednesday</b> 23 <sup>rd</sup> February			
0800-0915	KY with psychologist Both – Departmental teaching	Dr Rosenthal	
0930-1030	Both -Paediatric walkround	Nicola	
1030 -1130	Both -Nutrition and CF	Mary Gurd	
pm	Both – CF Respiratory clinic.	Dr Rosenthal	
<b>Thursday</b> 24 <sup>th</sup> February			

0900-1230	KY with psychiatrist at Maudsley Hospital. NR – Physio on Rose Ward	Nicola Collins	
	Talk with adult CF physician	Dr Di Bilton	
1330 -1630	CF ward	Dr Rosenthal and team	
Evening	Social evening	Dr Rosenthal, Jacquie Francis, Tony, KY and NR	Supper at the Patara Restaurant, Maddox Street.
<b>Friday</b> 25 <sup>th</sup> February			
0900-1300	Both – Home visit	With Pat Stringer	
1330 -1600	Both – CF Clinic		
<b>Saturday</b> 26 <sup>th</sup> February	Sightseeing.		
<b>Sunday</b> 27 <sup>th</sup> February	Both – Depart RBH for Heathrow. Depart Austrian Airlines flt 452 to Lviv via Vienna.		

**Key:** NR: Dr Nataliya Rohovuk, KY: Kateryna Yavna, TW: Tony Wolstenholme

### **Dr Rohovyk, CF physician, February 2011**

- To note how Doctors are organised at RBH for the care of patients with respiratory conditions (including CF).
- The value of having a multidisciplinary CF team with all members expert in their own fields.
- The absence of dietary input in the Ukrainian CF care regime and insufficient attention to the use of minerals and vitamins.
- A lack of a comprehensive CF scientific library in Ukraine and limited access to similar guidance on the internet.
- Some French CF Doctors gain their understanding of CF in UK.
- Prophylaxis is much to be preferred to treatment of CF related illness.

### **Katerina Yavna, Psychologist, February 2011**

First I want to say thank you for the possibility to visit London and Brompton hospital.

The most interesting moments for me was visiting doctor's clinics and day spent with psychologist Michele Puckey. But all other meetings were also interesting. I liked discussion with play specialist, it was nice to see physiotherapy and communication between doctors and families, to be present on outpatient consultation and see how specialists work. It brought a lot of new experience.

This time it was very interesting, but because it was for the first time it was often difficult to pick up what would be most interesting and useful. Now when I saw already something, it would be easier to choose. It is important to have good schedule. If it would be possible to come for longer period I would like to:

- Spend more time with Michele and see her work with families and patients. Also, to see how she cooperates with social workers and school nurse. I am interested in meeting other psychologists.
- Meet play specialist and spend some time with them to see how they work with children.
- Meet social workers and discover their work, because it is still a non-existing field in Ukraine.
- I am interested in cooperation with dietitian and visiting home care service.
- Visit sleep disorder department.

## **Katerina Yavna, July 2011**

**When:** June 20th 2011 till 29th June 2011.

**Where:** Royal Brompton Hospital, London SW3 6NP UK.

**Who with:** Michelle Puckey, Consultant paediatric psychologist.

**Why:** To further understand the psychological problems attendant on paediatric chronic diseases with particular reference to cystic fibrosis (CF) and as a result manage them better.

**How:** I attended with Michelle her therapy sessions with specific patients and accompanied her to the CF multidisciplinary meetings, weekly ward round and the weekly psychosocial meeting where social workers, play therapists, nurses and psychologists specifically discuss the emotional welfare of all the in-patients.

**What additional skills acquired:** I undertook UK level 2 children's safeguarding training. I also attended the annual paediatric asthma away-day where the overall management protocols for severe childhood asthma were being debated and revised in a multidisciplinary setting confirming that there is enormous psychological

overlap between all the paediatric chronic diseases, non adherence with treatment being the most obvious example. Attended training for psychologists, play therapists social workers and nurses on how to minimise work based stress and burn-out.

What I learnt and now apply: That paediatric psychology and psychologists are an integral part of the multidisciplinary team approach to any chronic disease not an add-on. Thus I now visit and advise on all CF admissions to my hospital, participate in the multidisciplinary ward rounds to anticipate rather than treat any psychological problems that may occur rather than wait for a large problem to become clear.

## RBH/CHI visit to Lviv, July 2011

### Program

3 July	4 July	5 July	6 July	7 July	8 July	9 July
Morning	Familiarization with Lviv Centre. Introducing members of Association of CF patients	Consultations and discussion of patients from Western region of Ukraine	Conference (Ukrainian presentations) — — Centre organisation,  — Diagnostics  — Treatment  — Physiotherapy  Presentation of Association of CF patients' President	Visit to Kyiv. Hotel lodging.  Meeting with Centre Specialists	Consultations and discussions of patients. Конференція та обговорення  Хворих  Presentation of Association of CF patients' President: Ms. Svitlana Skopychenko	Departure of the UK team
Mid-day	Arrival. Transfer. Lodging	Consultations and discussions of patients,	Consultations and discussions of patients from	UK professionals' workshop (your ideas).	Consultations of patients from Kyiv, Kharkiv,	UK professionals' workshop

		admitted to the Hospital	the Western Ukraine	Rosie Barnes presentation  <b>Press-conference</b>	Sumy, Cherkasy, ...	Centre presentation.  Rosie Barnes presentation
Evening	Short tour, rest time	Lviv Opera, Dinner, rest time	Lviv by night tour	Friendly dinner	Dinner, rest-time. Kyiv opera or city tour	<b>Press-conference</b>

## Presentations

- H.Makukh, L.Bober, M.Tyrkus<sup>1</sup>, O.Luga, O.Hnateyko<sup>1</sup>, O.Munduk: *Diagnostic challenges in Ukraine* ([English](#))
- Liudmyla Bober: *Organisation of Care for Children with Cystic Fibrosis* ([Ukranian](#)) ([English](#))
- Emma Dixon: *Airway Clearance in Paediatric CF* ([Ukranian](#)) ([English](#))
- Rosie Barnes: *The Importance of a Strong National Association* ([Ukranian](#)) ([English](#))
- Mark Rosenthal: *Cystic Fibrosis: (a) Diagnostic Dilemmas, (b) The New Problems* ([Ukranian](#)) ([English](#))
- Emma Dixon: *Airway Clearance in Paediatric CF* ([Ukranian](#)) ([English](#))
- Mary Jurd: *Dietary advice for young people with Cystic Fibrosis* ([Ukranian](#)) ([English](#))
- Pat Stringer: *A Co-ordinated Approach to CF Care* ([Ukranian](#)) ([English](#))

## Dr Mark Rosenthal, Consultant Paediatric Chest Physician

Dr Mark Rosenthal led the CF team in 2002 and 2011. These are his comments.

Myself, Emma Dixon (physiotherapist), Mary Jurd (dietician) and Pat Stringer (Specialist Nurse) as a paediatric CF team from the Royal Brompton Hospital visited the Children's hospital in Lviv from Sunday July 3rd and departed Saturday July 10th.

During our time in Lviv we were welcomed most affectionately as always. It is very sad that Dr Mindiuk, the head of the hospital and clearly a pioneer in Ukrainian healthcare had died so tragically in February this year.

Since our last visit in 2002 the overwhelmingly obvious change is the remarkable improvement in the overall health of the CF patients cared for locally. The local doctors led by Dr Bober religiously follow our printed CF guideline book and this combined with a greater access to medications in the intervening years meant that many of the children – indeed most of them – had nutrition and lung function that compared very favourably with our own in London. For this the entire Lviv team is to be congratulated. Children seen during that week looked after predominantly away from Lviv were in far poorer health and lag behind Lviv by some 10 years. In keeping with Lviv's pioneering ways, there is now even a paediatric psychologist (Katerina Yavna) who has visited us twice in London this year, as part of the Lviv team. She was regarded as outstanding by our psychologist, Michelle Puckey, when she was in London.

They still need encouragement to plot the patients' height, weight and lung function data to more easily delineate trends. They were encouraged to download and then print/photocopy UK growth charts for height weight and BMI. (<http://www.rcpch.ac.uk/growthcharts> for 0-4 years and <http://www.who.int/growthref/en/> for older children.

Lviv, compared with all other centres visited in the past, has easily been the most successful in my opinion as their receptivity and enthusiasm plus the culture fostered by Dr Mindiuk has all contributed to their success.

## **Emma Dixon, physiotherapist**

Physiotherapy Report for Ukraine Educational Visit and Conference July 2011. *Emma Dixon*, Specialist Paediatric Physiotherapist in CF Homecare, Royal Brompton Hospital

It was a pleasure and a privilege to return to Lviv after so many years as the physiotherapist in the visiting team. The improvements in paediatric cystic fibrosis management over the last 8 years were immediately evident in the children that were reviewed and in the management of the clinic set up. For example;

1. A team of 3 physiotherapists greeted me on my arrival to the hospital and enthusiastically whisked me away for consultations.  
*This demonstrated a great change in local practice and highlighted the importance of physiotherapy management in cystic fibrosis. I conducted lone consultations on my last visit allowing for very little carry-over.*
2. Large numbers of children reviewed during this visit did not have a productive cough.  
*On the previous visit, the majority had productive coughs. This implies improved home physiotherapy programs although I am aware that with improved access to antibiotics and readily available creon there are general improvements in health.*
3. All families were able to describe (but not always achieve- this is a worldwide issue!) a physiotherapy airway clearance technique not evident on the



previous visit. Good use of combination of exercise, airway clearance and posture exercises.

## **EDUCATION AIMS OF THIS VISIT**

- Demonstration and education of both ACBT (the active cycle of breathing technique) and Autogenic drainage as they are low cost therapy, are effective if used appropriately and pose no infection control risk.
- Importance of good assessment skills from the physiotherapist
- Problem-solving skills
- Ensuring physiotherapy regimens are appropriate for child's age, disease severity, family dynamics and progression for independence. Mainly Individualis.

I did demonstrate and discuss pros and cons of 'The Vest'. A new machine has been donated to the hospital but with no knowledge regarding its use.

## **RECOMMENDATIONS FOR FURTHER COLLABORATION**

- Educational visit by physiotherapist to the UK to consolidate and progress the above knowledge
- Attendance at specific Autogenic Drainage Course/Airway Clearance course (available usually at the European Conferences annually).
- Obviously a review by the RBH team in about 5 years!

Finally I wish to thank again our hosts, who provided both excellent professional and social programs for our visit. I have thoroughly enjoyed my time in Ukraine, learning a great deal myself and feel that the progress in physiotherapy management will be sustained.

## **Pat Stringer, Specialist Nurse**

This was my first visit to the hospital in Lviv and I was struck by several things:

Most of all, the warm welcome by all members of the team and their receptiveness to our exchange of knowledge and ways of practice, everyone was so keen to maximise the opportunities of our teams working together.

Also the fact that my colleagues Mark and Emma were so impressed by the development of the service and improvement in the general condition of the children since their last visit 9 years ago was very heartening.

It was very inspiring that the nurses I met with wish to develop a CF Nurse Specialist Role within the Lviv team.

Developments that I feel would strengthen the team in Lviv certainly include the development of a nurse specialist role to enable co-ordination of the service to families by proactive telephone follow up between hospital appointments especially when new treatments have been introduced and also providing a point of contact for parents again via telephone to access specialist advice when for example they are concerned about their child's condition or maybe learning about CF when their child is newly diagnosed.

I appreciate that many of the patients live a significant distance from the centre in Lviv. Though home visits would undoubtedly be very beneficial, the distances preclude this for some families. This is why I would suggest an initial focus on setting up a telephone service.

I feel sure that it would be beneficial for the development of this role for a nurse to visit our unit in RBH to observe our nurse specialist roles in action but it would be essential that they had a good understanding of English in order for this to be a viable proposition. In addition, from working together with my colleague Emma Dixon and the physiotherapists in the Lviv team, I feel sure it would be very beneficial for a physiotherapist also to visit our unit but again they would need to be able to communicate in English

I would be very happy to discuss these thoughts further and would like to say how much I appreciated the opportunity given to me to be able to visit the Lviv team. I feel privileged to have been able to participate in the project; this was an experience that I will treasure.

## **Mary Jurd, Dietician**

Dietitian Report: Clinics from Monday 4th – Friday 8th July 2011

### **OVERALL IMPRESSION**

Patients who were seen at Lviv clinic had far better nutritional status than I had expected to see based on impression and information that I received from colleagues who had visited the centre 9 years ago. The majority of patients seen in the clinic had good height, weight and growth. As a general rule those children who had a tendency to struggle more with poor weight gain and faltering growth were the ones who had worse pulmonary status. However this could probably be reflected in most CF clinics regardless of the location: it highlights that children with more frequent exacerbations and hospital admissions for IV antibiotic courses need to be carefully monitored.

I believe the improvement in nutritional status can be credited to the medical team in their increased awareness of the impact of nutrition in Cystic fibrosis. In addition to this the availability over the last few years of the free provision of the pancreatic

enzyme replacement therapy 'Creon' has reflected well, not only on children's weight gain and growth, but it also has reduced their parents' anxiety about being able to afford this medicine.

Unfortunately there is no specific individual person who takes responsibility for just this area and a Dietitian would be a valuable addition to the team (or if not a dietitian per se then a person who could adopt similar responsibilities).

## **DIETETIC SUGGESTIONS BASED ON MY OBSERVATIONS FROM CLINIC**

### **1. Monitoring growth and nutritional status**

All the children had been weighed and height measured and this had been documented.

However we felt strongly during our visit that height and weight mean very little unless you put them in a context of growth. This is why growth charts are extremely helpful. I provided some of the children with growth charts during our visit but it is important to keep these safe and continue to plot children's growth.

Ideally the WHO growth charts should be used along side the standards of anthropometric measurements in children: but I appreciate there is a cost implication for this.

Monitoring growth can be key to ensuring children are getting enough nutrition, appropriate enzymes, are not salt depleted and even for helping to identify children who may be developing CFRD.

### **2. Oral Nutritional Supplements**

These are quite often unpopular with the children, and in Lviv some children when they were being asked to drink 500ml per day of the unflavoured feeds which are generally designed to be used as nutritionally complete tube feeds (meaning not clear). These supplements were expensive even compared to UK prices. We felt that in many cases it might be a more effective use of money to redirect the funds that families spend on these supplements into other areas of their treatment.

At the conference there seemed to be a very large presence from companies such as Fresenius and Nestle: I think it is important to consider that these companies have large marketing budgets and that they can sometimes give the impression that children 'need' these products. But there is no 'magic liquid' that is going to solve a situation where a child has poor growth. Studies in CF children have shown that

having a diet high in fat and regular meals can be just as effective as using oral nutrition supplements.

Additional calories can be easily and economically added to food by using traditional Ukrainian full fat dairy products fats and oils and ensuring frequent high calorie meals and snacks. This, when combined with appropriate pancreatic replacement therapy, is usually sufficient to ensure adequate energy intake.

Obviously, in cases of acute exacerbation and children who are less well overall, then this situation needs to be reviewed. This is why it would be helpful to have a member of the team whose particular interest would be to focus on this area.

### **3. Education and literature**

Providing information for parents patients at appropriate time. Consider discussing with parents – Balanced meals for adequate calcium and iron etc, high energy diets, salt, understanding the fat contents of foods, checking vitamin levels and doses. Providing parents with plans for when children are more unwell.

The CF trust have good diet sheets of eating for infants, children and young people: it would be great if these could be adapted and translated for the Ukrainian population.

### **4. Someone in the team to lead on Nutrition:**

Consider having a designated person who takes responsibility for monitoring growth and nutritional intake and status.

A person who can communicate with families to offer support and advice on weight gain at home and to liaise with catering staff to ensure adequate nutrition during hospital stays.

As a starting point I would suggest this member of the team should have:  
Responsibility for weighing and heighting ( I'm not sure this is a verb!) in clinic and hospital admissions and ensuring that these measurements get plotted correctly on growth charts (and ensuring the growth charts don't go missing!)

Be able to identify faltering growth.

A good background in physiology and understanding of the basics of human nutrition.

Be able to understand and liaise with the hospital catering staff to ensure children are receiving optimal nutrition on the ward when they are inpatients. Also the

appropriate use of nutritional supplements in a few circumstances such as enteral feeding- although I think this would require more training.

And with outpatients be able to offer practical tips and advice to parents to improve day to day nutrition. Therefore knowledge of food and cooking is important.

Someone who not necessarily adjusts enzyme dosage but who is able to understand how different foods might need different amounts of Creon. Be able to identify this in diet histories and patients symptoms and can liaise with the doctors on any changes that might need to be made.

An overall understanding of how nutrition impacts on nutrition in CF and a passion for promoting this to the patients and the rest of the team.

### **Typical food prices in Lviv, 3rd July 2011.**

Exchange rate used £1 = Hry 12

Whole chicken	£1.60p / kilo
Tomatoes	£0.75p /kilo
Apricots (Crimean)	£2.00p/ kilo
Smetana (30% fat)	£1.70p/ kilo
Hard cheese	£5.33p/ kilo
Milk	£0.92p/ litre
Mayonnaise	£1.65p/ kg
Olive oil (Italian)	£3.33p/ litre

Sala (almost 100% fat)	£2.90p/ kg
Tvorog (£cream cheese£)	£1.83p/ kg
Butter	£5.63p/ kg
Yogurt (Danone)	£0.23p/ 90gm
Yogurt drink (Galichina)	£0.58p/ bottle
Honey	£4.40p/ kilo
Beeswax	£12.50p/ kilo

We were advised that the main meal of the day is typically a meat dish. Fish is not often eaten. A popular evening meal is Varenyki whose fillings can be very varied: Quote (Wikipedia) Varenyky are square or crescent-shaped dumplings of unleavened dough stuffed with sauerkraut, cheese, mashed potatoes, cabbage, meat, hard-boiled eggs (a Mennonite tradition) or a combination of these, or with a fruit filling. Varenyky are very popular in Ukraine. During dietary consultations, we found that most CF children eat kasha ( a form of porridge, often made with buckwheat) either for breakfast or in mid morning.

### **Dr Bober, PhD, Western-Ukrainian Specialized Children's Medical Centre**

I appreciate that, from your point of view, the whole meeting, the conference and the clinics were a success.

From my side I would like to thank you, Tony, for impeccable organization of the visit and for fruitful work. Professionalism of Dr. Rosenthal's team, without exaggeration, made a huge input into solving the Cystic Fibrosis problem in Ukraine.

### **Dr. Sitlana Skopychenko, President of Ukrainian Association of help to patients with CF**

Ukrainian Association of help to patients with CF was founded at the end of 2009 to represent CF-patients` rights at the governmental level.

Our today`s achievements are:

1. We have become a member of Cystic Fibrosis Europe.
2. We have got the national statistic of the patients with CF in Ukraine. We must say that there were no national statistic at all, but because of our apply we have got it from the Ministry of Public Health of Ukraine.
3. We have become a member of the All-Ukrainian Association “Nations Health”, whose aim is to protect patients` rights in Ukraine.
4. We have taken a part at the conference “Care for CF-patients” in Lvov (Ukraine), where doctors all over the Ukraine were presented;
5. Members of our association were represented at the Cystic Fibrosis Europe Annual General Meeting in Hamburg, June 7, 2011;
6. Thanks to our assist the Lvov regional centre of CF get for free drainage apparatus for cleaning lungs from the “The Vest” company;
7. We are working under database of Ukrainian CF-patients;
8. Connecting with national professionals of CF-sphere (doctors, psychologists, social workers etc.);
9. Organizing volunteer movement;
10. Our volunteer have made a research “Model of psychosocial intervention of CF-patients and their families”.

Our future plans are:

1. We have to write the National CF-program so that our patients would have an opportunity to obtain government assist. That is why we have to lobby such program at the government level – Ministry of Public Health of Ukraine;
2. We have to set up a CF-web-site to make it easier to communicate with CF-patients, professionals, volunteers and also sponsors;

3. We are planning to test Model of Psychosocial intervention that our volunteer have created;
4. Making researches about the needs and problems of CF-patients and their families;
5. Make a huge information campaign to inform Ukrainian society about problems of CF.

President of Ukrainian Association of help to patients with CF

Dr. Sitlana Skopychenko

### **Tony Wolstenholme, Project Manager: final remarks**

First and foremost, as observed above, the most heartening features of the visit to Lviv were the improvement in the health of the children and the professional competence of the team led by Dr Lyudmila Bober.

The hospitality we were afforded in Lviv and in the Carpathians was superb.

It was disappointing that the Kiev leg of the project was cancelled at short notice.

It was a privilege to watch the RBH paediatric CF team at work: so caring, professional, dedicated and with good humour.

We shall try to bring a physiotherapist and a specialist CF Nurse from Lviv to RBH to learn more about these roles

It requires more study and correspondence with Dr Svitlana Skopychenko to identify what help can be given to the Ukrainian Association of Help to CF Families.

We are delighted to have saved over £1000 on the cost of this visit, because of the generosity of our hosts and team members paying for themselves on a number of occasions