

European mental health advocacy groups and politicians unite for first time ever to address lack of access to vital information for people affected by schizophrenia

Submitted by: Ogilvy Public Relations Worldwide (UK)

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– “Discover the Road Ahead”, a new patient and carer initiative, set to help improve the lives of millions in Europe –

[Stockholm, 09 October 2004] – Eighteen pan-European and national mental health advocacy groups representing millions of people affected by schizophrenia, have joined together for the first time as INFORMED, International Network For Mental Health Education, to launch an initiative which aims to improve access to information on this serious, yet treatable disease. “Discover the Road Ahead”, a comprehensive and user-friendly resource that gives people with schizophrenia and their families information, advice and support has been launched today at the 17th Annual Meeting of the European College of Neuropsychopharmacology (ECNP).

European Politicians Endorse Initiative

The new initiative from INFORMED has been welcomed by Members of the European Parliament, who recognise the need for people with schizophrenia to have greater access to information about their symptoms, treatments and side effects to help improve their quality of life and that of those caring for them. Dr Charles Tannock MEP, a former psychiatrist, said “I am delighted to support the launch of the INFORMED initiative. I spent my professional career treating patients with schizophrenia and all measures taken to relieve their suffering and better inform the families of the patients is extremely welcome.”

Rodney Elgie, President of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe), Europe's biggest umbrella patient organisation in mental health, who is leading the initiative said: “We know that knowledge is power, and as a person affected by schizophrenia, if you aren't informed about your illness, your access to the latest treatments, rehabilitation and support, accommodation, and employment are severely reduced.”

“It's the aim of INFORMED, through initiatives such as “Discover the Road Ahead”, to bring about greater and equal accessibility to user-friendly and up-to-date information, particularly on the latest treatments, so that people with schizophrenia and their carers can make informed choices about their lives and management of this condition,” he continued.

Research Reveals Information Gap Impacts on Provision of Care

The development of this unique handbook has come about as a direct result of recent research. Whilst numerous surveys show that information, and access to it, is a critical aspect in providing good care and helping people to manage their condition [1], new data highlight that there is a serious information gap. One in four carers said they did not have any information to help them and that often information is denied or withheld. Among those who do have some information, one in three revealed that they do not have enough. [2]

Carers want to know a lot more about medication, specific mental health problems, new treatments, local service provision and coping strategies. Patients felt current information fell between two stools – leaflets did not provide sufficient depth of information, particularly for those who had recently been diagnosed with schizophrenia. In comparison, the Internet and textbooks overwhelmed and put off other patients, particularly as they were not considered to be user-friendly. [3]

“Access to information on the latest treatments available, particularly those that patients can adhere to, is critical to improving the quality of life for people with schizophrenia so that they can get better and make a contribution to society. “Discover the Road Ahead” is a much needed resource that can deliver this essential information,” said Preston Garrison, Secretary-General & CEO, World Federation for Mental Health.

“Much needed” Resource Piloted in UK

“Discover the Road Ahead” provides helpful information on detecting the early signs of schizophrenia, how to deal with diagnosis, the progression of the condition, and outlines the latest treatments and support that is available. The handbook was produced by people with first-hand experience of coping with schizophrenia, including advocacy groups, health care professionals and university professors. The resource was piloted with people with schizophrenia in the UK, who reported it to be “different, very much needed, easy to read, open and accurate with useful case studies from a range of ethnic groups”.

Early Access to Information Essential

Schizophrenia, which affects 1 in 100 people across Europe, is a serious brain disorder, which is characterized by symptoms that make it difficult for a person to tell the difference between real and unreal experiences, and to organise their thoughts. In addition, the diagnosis of schizophrenia, more than any other illness, is feared and misunderstood. It is therefore critical that information is available to help people understand their condition so that they can seek appropriate help in the early stages of this serious, yet treatable disease.

“Discover the Road Ahead” is being made available across Europe to patients with schizophrenia and their carers free of charge.

For your copy contact INFORMED@uk.ogilvypr.com

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Notes to Editor:

Ø Schizophrenia is a chronic and persistent brain disorder and one of the most severe common mental illnesses.

Ø Schizophrenia occurs in all cultures and affects approximately one in one hundred people worldwide.

Ø Schizophrenia interferes with a person's ability to think clearly, manage emotions, make decisions and relate to others. This illness tends to manifest itself in early adulthood and is characterized by positive symptoms, such as hallucinations, delusions, and paranoia, as well as negative symptoms, such as social withdrawal and emotional flatness. While there is no cure, it is a treatable illness.

Ø World Mental Health Day is on Sunday 10 October 2004. The focus of this year's campaign is the relationship between physical and mental health.

References:

[1] Rethink data on file

[2] Rethink, 2003. Who Cares? The experiences of mental health carers accessing services and information, p.7.

[3] Mentality UK data on file

INFORMED is the network of the following organizations:

Association of Community Mental Health Nurses of Ireland, Republic of Ireland; Associazione per la Riforma dell'Assistenza Psichiatrica (ARAP), Italy; Associazione Italiana Donne Medico, Italy; European Federation of Associations of Families of People with Mental Illness (EUFAMI); German Schizophrenia Network, Germany; Mental Health Europe, Belgium; mentality, UK; National Coalition of Associations of Patients Suffering from Chronic Diseases (CnAMC), Cittadinanza Attiva, Italy; Organisation of the Carers and Families of People with Serious Mental Illness, Croatia; Panhellenic Association for Families of Mental Health, Greece; Penumbra, UK; Rethink, UK; Sane, UK; Schizophrenia Solidarity Association of Izmir, Turkey; The Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe); Union Nationale des Amis et Familles de Malades Psychiques (UNAFAM), France; Vereinigung der Angerhörigen van Schizophrenie/Psychisch-Krnaken (VASK), Swizerland; World Federation of Mental Health, USA.