Experts call for urgent change in the care of young adults with IBD

(Vienna, October 19, 2016) Today, world leading digestive health experts are presenting a pioneering new programme that could have a significant impact on the quality of life of young adults living with inflammatory bowel disease (IBD). Experts believe that the programme could help combat the poor and, in some cases, life-threatening care offered to young IBD patients across Europe.

IBD can be an extremely debilitating condition and one of the key issues concerning clinicians is the transition from paediatric to adult care. This is fraught with difficulty and, with the incidence of paediatric IBD currently rising, many young people enter adult care with extreme and complex forms of the disease which is often mismanaged. The lack of support and effective management during the transition can have severe consequences for both the individual and the healthcare system.

The Berliner TransitionsProgramm (BTP), established in Germany, has reported its first successes in the safe and effective transition of childhood IBD patients into adult care. The programme lasts two years for each child and involves close collaboration between paediatricians and adult care colleagues.

Professor Britta Siegmund, a member of the BTP Task Force discussed the encouraging findings at UEG Week 2016. “Following the success of results in other disease areas, IBD was incorporated into the programme two years ago. Transitioning programmes are initiated in the paediatric setting and involve a gradual process aimed at building the young person’s understanding of their condition to help prepare them and their families for a move into adult care. So far, our experience demonstrates that the young people who have taken part have arrived into adult care very positively.”

One in four cases of IBD are diagnosed during childhood and over 50% of sufferers believe that IBD negatively affects their education. “With the change of care occurring at such a crucial age for our patients, it highlights the importance of a smooth and supportive transition to enable young adults to lead normal lives and prevent the disease from impacting their education and lifestyle” says Professor Siegmund.

As well as IBD, the BTP also includes other long-term paediatric conditions, such as juvenile diabetes, epilepsy, arthritis, kidney disease and asthma. When a patient is included in the programme, a case manager is assigned who takes care of all the practical issues, maintains contact with the patient throughout the process and ensures that they are comfortable throughout the programme. Where needed, the patient can see both their paediatrician and their new treatment team during the transition.

Providing all the materials, structure and support required to transition children safely, Professor Siegmund hopes that the success of the programme will provide a framework that can be incorporated across the rest of Europe. She explains, “The BTP can serve as a role model that can be adapted to the health service of each country. One of the critical success factors for the programme is to ensure that children are transitioned into the care of specialists who really understand adolescents and are willing to invest the time in them. All physicians who agree to take part in the programme fulfil this requirement and are committed to the success of the project.”

For more information on the BTP, please visit:
References
1. UEG EU Affairs. Paediatric Digestive Health Across Europe: Early Nutrition, Liver Disease and Inflammatory Bowel Disease. Available at: https://www.ueg.eu/epaper/UEG_Paediatric_Digestive_Health_Report/index.html
4. The IMPACT Survey, 2011, EFCCA. Available at: http://efcca-solutions.net/

Notes to Editors
For further information, or to arrange an interview with Professor Britta Siegmund, please contact Luke Paskins on +44 (0)1444 811099 or media@ueg.eu

About Professor Britta Siegmund
Professor Siegmund is from the Medical University of Berlin and is a member of the Berliner TransitionsProgramm in inflammatory bowel disease. Her interests include contributing towards the understanding of inflammatory bowel disease and identifying possible novel therapeutic targets.

About Professor Gigi Veereman (UEG Spokesperson)
Professor Veereman is a member of the UEG Public Affairs Committee and Secretary General at the European Society of Paediatric Gastroenterology, Hepatology and Nutrition.

About UEG Week
UEG Week is the largest and most prestigious gastroenterology meeting in Europe and has developed into a global congress. It attracts over 14,000 participants each year, from more than 120 countries, and numbers are steadily rising. UEG Week provides a forum for basic and clinical scientists from across the globe to present their latest research in digestive and liver diseases, and also features a two-day postgraduate course that brings together top lecturers in their fields for a weekend of interactive learning.

Register to attend UEG Week.

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UEG, or United European Gastroenterology, is a professional non-profit organisation combining all the leading European societies concerned with digestive diseases. Together, its member societies represent over 22,000 specialists, working across medicine, surgery, paediatrics, gastrointestinal oncology and endoscopy. This makes UEG the most comprehensive organisation of its kind in the world, and a unique platform for collaboration and the exchange of knowledge.

To advance standards of gastroenterological care and knowledge across Europe and the world, UEG offers numerous activities and initiatives, including:

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- **UEG Education**, the universal source of knowledge in gastroenterology, providing online and classroom courses, a huge online library and delivering the latest GI news, fostering debate and discussion
- **Training Support**, funding for innovative training and educational programmes, as well as international scientific and professional co-operations
- **UEG Journal**, published bi-monthly, covering translational and clinical studies from all areas of gastroenterology
- **EU Affairs**, promoting research, prevention, early diagnosis and treatment of digestive diseases, and helping develop an effective health policy for Europe

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