FIND-ID Seeks to Improve Early Diagnosis and Treatment of Congenital Immunodeficiencies

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In order to recognize congenital immunodeficiencies in patients at an earlier stage, thereby improving their life expectancy and their quality of life, doctors from the German Jeffrey Modell Foundation centers, and representatives of the Deutsche Selbsthilfe angeborene Immundefekte (dsai e.V.)—a German association for patients with Primary Immunodeficiencies—gathered at the invitation of Fred and Vicki Modell for the 2008 European Society for Immunodeficiencies (ESID) Congress in the Dutch city of ’s-Hertogenbosch. As a result of that meeting, Professor Tim Niehues (HELIOS Clinics, Krefeld, Germany), Professor Volker Wahn (Charité, Berlin) and Gabriele Gründl (dsai e.V.) developed a plan for a network initiative: FIND-ID was born.

The creators of FIND-ID are focused on achieving early diagnosis and treatment for patients with congenital immunodeficiencies (primary immunodeficiency diseases – PID). Of the approximately 40,000-100,000 persons affected throughout Germany, only about 3,500-4,000 patients are currently diagnosed. Since its foundation in 2008, the work of FIND-ID has contributed to improving the rate of diagnosis and has increased awareness of the condition.

The number of patients documented in the ESID registry increased from 785 patients in 2009 to 1,978 patients in 2014. The campaign group has observed that a PID condition is still often diagnosed too late or the diagnosis is delayed by several years. Usually, the situation for adults is worse than that of children and an effective therapy can often only be started very late or not at all.

FIND-ID has two main objectives: to close the knowledge gap about PID among medical specialists potentially involved in the treatment of patients with PID like ENT doctors, dermatologists, pneumologists, gastroenterologists, oncologists, rheumatologists, and others; and to improve the communication between those medical specialists and the specialized immunodeficiency treatment centers who are the core members of the FIND-ID physicians network. By doing that, the cooperation with the immunodeficiency centers on complex laboratory diagnostics or on serious decisions about therapy will be strengthened and doctors will be educated about PID. Only appropriate diagnostic instruments should be used for a diagnosis and patients should be analyzed in relation to their heredity if there are cases of genetic defects.
in their family history as only a precise and early therapy can prevent irreversible organ defects and premature death. FIND-ID wants to improve the patient’s quality of life and to support all doctors involved in the therapy process.

**FIND-ID CAMPAIGNS FOR IMPROVED QUALITY OF CARE**

Ideally, patients and the physicians who treat them should be linked to a center specializing in primary immunodeficiencies. This ensures that the patients can be treated in accordance with the latest developments and insights of medical science. The number of immunodeficiencies known to date with their complex symptomatology is increasing but the number of patients is minimal. This calls for close cooperation between doctors and specialists.

**FIND-ID STANDS FOR FAIR PARTNERSHIP**

The network sees open communication as the basis for successful cooperation. Information loss between network partners must be avoided, and all those involved in treating the patients must be fully and continuously informed of everything they need to know for that treatment. These communications, along with prompt feedback, creates a robust network. This will also allow a joint therapy plan to be implemented along with primary treatment instances.

**NEWBORN SCREENING FOR SEVERE CONGENITAL IMMUNODEFICIENCIES MUST BE IMPLEMENTED**

“It is high time that severe congenital immunodeficiencies be added to the existing screening catalog for the newly born,” says Professor Dr. Tim Niehues, Director of the Center for Pediatric and Adolescent Medicine at the HELIOS Clinics in Krefeld, Germany. Moreover, the creator of the FIND-ID physicians’ network is delighted that, thanks to the possibilities offered by screening, immunology has “shifted as never before into the focus of preventive medicine.”

In the United States, severe combined immunodeficiencies (SCIDs) are already on the list of illnesses for which newborns are screen tested. This is not yet the case in Germany; the conditions covered by screening include congenital metabolic and hormone deficiencies, but, to date, no congenital immunodeficiencies. In particularly severe forms of congenital immunodeficiency—the so-called SCIDs—it is vital that the diagnosis be made very soon after the birth of the child so that an appropriate therapy can be initiated as soon as possible.

“One of the key objectives of FIND-ID is that newborn screening for SCID should be implemented reliably, economically, and, last but not least, in a patient-friendly and ethically justifiable manner,” Niehues declares. In this respect, FIND-ID works together with the Association for Pediatric Immunology (API), and with the Pediatric Immunology Working Group of the German Society for Immunology. “Such cooperation is of vital importance,” Niehues emphasizes. “Working via these specialist associations, FIND-ID can also involve policy-makers in its objectives.”

As a result of intensive discussions between the API and the National Association of Statutory Health Insurance Funds (GKV-Spitzenverband), in 2014 the latter requested the German Federal Joint Committee (G-BA) to assess newborn screening for congenital immunodeficiencies. Following standard procedures for assessing health technologies in Germany, the German Institute for Quality and Efficiency in Health Care started to evaluate SCID screening and published a preliminary report in the summer of 2016 with the following conclusion: “Newborn screening for severe combined immunodeficiencies (SCID screening) in combination with an infection-prophylactic therapy leading to curative therapy is indicative of a benefit.”

FIND-ID and API submitted brief statements on this preliminary report supporting the introduction of a nationwide SCID screening.

Based on the positive result of the benefit assessment, it seems likely that the final report will be positive, paving the way for the introduction of SCID screening in Germany.

“Especially in the adult sector, the awareness of this disease is not yet as well developed as we would wish it to be. It was for this reason that Professor Volker Wahn of the Charité in Berlin, Gabriele Gründl, Chair of the dsai patient organization for congenital immunodeficiencies, and I set up FIND-ID in 2008.” For registered resident doctors in particular, FIND-ID provides fast and easy access to experts, to whom they could directly transfer patients with a suspected congenital immunodeficiency.

**“WE NEED EVEN MORE RESIDENT PHYSICIANS IN FIND-ID.”**

It is this very network concept that Niehues regards as being one of the key advantages of a membership in FIND-ID. “As a physician, you then have faster access to information, and we are represented with ID centers in almost all regions of Germany, so that resident doctors can quickly find an expert near to where they are.” He argues the case for further expansion of the network—with hub centers, smaller centers, and resident physicians—throughout Germany. “It would be splendid if we could have even more partners in private practices, so that we will begin to see more and more contact points for patients.”