

## **Registry for Histiocytic Disorders Information**

### **Introduction**

The Registry for Histiocytic Disorders is for adults with any type of histiocytosis and has been set up under the supervision of the Histiocyte Society at the Elisabethinen Hospital in Vienna, Austria.

Even though histiocytosis is probably as common in adults as in children, much less is known about histiocytosis in adults. This includes how it affects people, the best way to treat it and what happens during the course of the illness. We will submit data for adult patients with histiocytosis to the registry using a secure online website specially created for the Registry. The database is in English and German.

### **Aims of the Registry**

The Registry for Histiocytic Disorders has been set up as an international effort to improve knowledge, understanding and treatment of adults with histiocytosis. In order to produce the best quality data it is necessary to have information from as many patients as possible. Its objectives are:

- To collect information from multiple national databases to answer research questions about diagnosis, treatment and follow-up of adult patients
- To develop standard treatment protocols and help adult patients to access clinical trials of new drugs
- To help doctors advocate for patients with histiocytosis by providing information about how people's lives are affected and what healthcare they require to optimize their quality of life

### **Information collected by the Registry**

Your year of birth, gender, and ethnicity are required because it is useful to know what group of patients are most often affected, for example young or old, male or female. The registry will also know you are a UK resident because we are submitting your data. Your participation is anonymous since there is almost no chance that you could be identified from this information. The information will also be treated confidentially and only released to researchers who want to make a contribution to understanding your disease. Although the fact that you have a rare disorder is linked to your identity, your data will only ever be published in a completely anonymous way as part of a cohort or group of patients rather than you as an individual. Information about your illness needs to be as complete as possible. Most of this will come from your medical records, pathology reports and x-rays or

scans. You may discuss this further with your doctor and let us know if there is anything that you do not wish to be disclosed.

### **Data Security Information**

The UK Histiocytosis Registry has a duty and responsibility for safeguarding your information and how it is used. We have reviewed the security of the Histiocytic Disorder Registry database and are satisfied that it meets the appropriate standards. The Registry team headed by Dr Girschikofsky uses German IT Company, Celsius 37 (<http://www.celsius37.com/>), to manage the database. This company specializes in medical databases and already delivers a web-based database for 11 hospitals in the region of Upper-Austria, including the Elisabethinen Hospital. The database is hosted on a secure server by the IT company T-Systems Austria (<https://www.t-systems.at/>). A letter from T-systems giving details of their security precautions is included below.

### **Contact Details for the Registry Coordinator**

Dr. Michael Girschikofsky  
Elisabethinen Hospital  
Department of Medicine I  
Center of Hematology and Stem Cell Transplantation  
Hemostasis and Medical Oncology  
Fadingerstr. 1, 4020 Linz, Austria  
Tel.: 0043 732 7676 0  
Fax: 0043 732 7676 4416  
E-mail: [michael.girschikofsky@elisabethinen.or.at](mailto:michael.girschikofsky@elisabethinen.or.at)

## T-Systems

T-Systems Austria GesmbH  
Rennweg 97-99  
1030 Wien

To Whom It May Concern,

Below is an outline of the T-Systems Austria service for the server extgir01 for KH Elisabethinen Linz and the controls in place to ensure accessibility, security and privacy of our data.

### Physical Security

This T-Systems Austria server is located within T-Systems data centre at ODC, Richard-Neutra-Gasse 10 in 1210 Vienna. Access to the building is monitored around the clock (7x24) by on premises security staff. Access to the data centre is further controlled through a badging access system.

### Data Protection

Backup is created four times a day by server snapshots which are stored on a redundant storage cluster for 31 days. The backups are also stored a second time on a separate storage volume.

### Availability

The application server reside on a multi-node VMware vSphere virtual cluster and data is housed on a redundant storage array. Power redundancy is provide through an N+1 UPS which is itself backed up by dual diesel generators.

All server hardware and VMware systems are monitored for uptime and availability 24/7. Support is provided by T-Systems server admins 8x5.

### Data Security

The server is behind a T-Systems firewall and only allows access to ports 22, 80 and 443.