Dear Sir or Madam,

the "PH Self support group Germany" is hereby seeking contact with you to draw your attention to the rare metabolic disease "Primary Hyperoxaluria" (short: PH). In the three forms of PH, excessive production of oxalate in the liver leads to increased urinary oxalate excretion, resulting in recurrent kidney stones or progressive nephrocalcinosis and often to tend stage renal failure. Then blood oxalate levels rise and oxalate is deposited throughout the body.

Despite recurrent kidney stones and often progressive kidney calcification, PH is still not adequately diagnosed in many patients today. Almost 40% of adult patients are diagnosed with renal failure or after a failed transplantation. A later problem of the disease, which then turns it into a multisystemic disease, is mainly the systemic deposition of oxalate in patients with chronic kidney disease. Currently, only a liver transplantation can be performed curatively for PH I. This should be avoidable today if diagnosed early and treated in time.

Before serious symptoms arise due to PH, those affected (often already in childhood) often develop kidney stones. And this leads to our approach to significantly reduce the undetected proportion of patients with recurrent kidney stones or progressive nephrocalcinosis in adulthood, but without diagnosis.

We kindly ask you to test 24 h collected urine or, in case of renal insufficiency, blood from your patients with the above mentioned symptoms for elevated oxalate levels. Also, the detection of 100% calcium oxalate stones (mostly monohydrate stones) may give a clue. Since PH develops "creepingly", not only the current investigations are of interest, but also those from previous years.

If results are positive, the patient is welcome to contact us (info@PH-Selbsthilfe.de). The further procedure will then be discussed with specialized colleagues, in Germany for example with the German Hyperoxaluria Center.

Soon there will be new treatment options, the so-called "RNA interference" treatment, which will significantly help the patients. Here, a specific enzyme in the liver is blocked, thus suppressing oxalate production. The RNAi medication must be injected under the skin at regular intervals. So it is not a gene therapy. In clinical studies excellent results have already been achieved, e.g. the oxalate excretion has been reduced back to normal values.

As already mentioned, the patients are not only children, the majority of known patients are adults. The latest developments in the field of PH treatments give us great hopes that renal failure or even a combined liver/kidney transplantation can be prevented and with the appropriate treatment a normal life is possible.

Please help us to give the still undiscovered patients this chance to live a normal life.

With our kind regards
PH Selbsthilfe (info@ph-selbsthilfe.de)

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PH
PRIMARY HYPEROXALURIA
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