

Resource Summary Report

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RDCRN Patient Contact Registry

RRID:SCR_004369

Type: Tool

Proper Citation

RDCRN Patient Contact Registry (RRID:SCR_004369)

Resource Information

URL: <http://rarediseasesnetwork.epi.usf.edu/STAIR/professional/register/index.htm>

Proper Citation: RDCRN Patient Contact Registry (RRID:SCR_004369)

Description: A portal specifically for patients (and their families) with sterol and other related disorders where they can register themselves with STAIR in order to be contacted in the future about clinical research opportunities and updated on the progress of the STAIR research projects. An online Registry form exists for all the BVMC disorders currently being studied.

Synonyms: STAIR Contact Registry, Rare Diseases Clinical Research Network Patient Contact Registry

Resource Type: patient registry, people resource

Keywords: sterol, patient registry, rare disease, cerebrotendinous xanthomatosis, mevalonic aciduria, hyperimmunoglobulinemia d with periodic fever syndrome, niemann-pick disease type c, sitosterolemia, sjogren-larsson syndrome, smith-lemli-opitz syndrome

Related Condition: Cerebrotendinous Xanthomatosis, Mevalonic Aciduria, Hyperimmunoglobulinemia D with Periodic Fever Syndrome, Niemann-Pick Disease Type C, Sitosterolemia, Sjogren-Larsson Syndrome, Smith-Lemli-Opitz Syndrome

Funding: National Institutes of Health

Availability: Free and anonymous for patients

Resource Name: RDCRN Patient Contact Registry

Resource ID: SCR_004369

Alternate IDs: nlx_143699

Record Creation Time: 20220129T080224+0000

Record Last Update: 20260829T183058+0000

Ratings and Alerts

No rating or validation information has been found for RDCRN Patient Contact Registry.

No alerts have been found for RDCRN Patient Contact Registry.

Data and Source Information

Source: [SciCrunch Registry](#)

Usage and Citation Metrics

We found 1 mentions in open access literature.

Listed below are recent publications. The full list is available at [ASWG](#) .

Romero Subir??n F, et al. (2018) Feature-Based Framework for Inspection Process Planning. Materials (Basel, Switzerland), 11(9).