

# Resource Summary Report

Generated by RRID on Aug 7, 2026

## 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:** people resource, patient registry

**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:** 20260807T042606+0000

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## 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.

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## Data and Source Information

**Source:** [SciCrunch Registry](#)

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## Usage and Citation Metrics

We found 1 mentions in open access literature.

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

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