ABOUT US

RACC-UK is a registered patient led organisation for patients and families who suffer from Autoinflammatory conditions. We also help those who are undiagnosed, yet symptomatic.

We are also part of the European Reference Network, RITA as a RIPAG member, as well as being registered as a stakeholder for NHS Clinical Reference Groups relevant to Autoinflammatory conditions.

(Disclaimer: All information has been approved by the Medical Board in 2018)

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RARE AUTOINFLAMMATORY CONDITIONS COMMUNITY- UK®



Are you #AutoinflammatoryAware?

Examples of Autoinflammatory conditions:

Periodic fever, apthous stomatitis, pharyngitis and adenitis (PFAPA)

Familial Mediterranean Fever (FMF)

TNF receptor - associated periodic fever (TRAPS)

Cyroprin- associated periodic syndrome (CAPS)

Mevalonate Kinase Deficiency (MKD)

Familial cold autoinflammatory syndrome - 2 (or NLRP12)

Deficiency of interleukin - 1 receptor antagonist (DIRA)

Pyogenic sterile arthritis, pyodema gangrenosum and acne syndrome (PAPA)

Blau Syndrome

Majeed Syndrome

Generalised pustular psoriasis or deficiency of interlukin - 36 receptor antagonist (GPP or DITRA)

Idiopathic Pericarditis

Systemic Juvenile Idiopathic Arthritis (SJIA)

Scleroderma

Autoinflammatory conditions are not to be confused with autoimmune conditions such as Rheumatoid Arthritis or Crohn's Disease.

Autoinflammatory conditions are rare and complex. They are genetic and caused by an 'innate immune response, whereas autoimmune conditions are caused by an 'adaptive' immune response.

<u>Symptoms commonly displayed in</u> Autoinflammatory conditions:

Fever

Rigours

Severe Fatigue

Sore throat

Rashes

Gastrointestinal issues

Oral and/ or genital ulcers

Inflammation of organs, joints and skin

Enlarged lymph glands

Blood Tests

High C-reactive protein (CRP)

Anaemia (HB)

Serum Amyloid A (SAA)

We will support patient and families so that they:

Can access the right treatment through the NHS

Improve and fulfil their potential

Feel less isolated through our online community

Learn about the emotional and physical effects of Autoinflammatory conditions

Receive coordinated care

Know how to apply for Disability/ Sickness benefits for financial support such as Disability Living Allowance (children), Personal Independence Payment, Attendance Allowance, Employment and Support Allowance and Carers Allowance

Get Educational Support



http://rita.ern-net.eu/