

NDIS: Primary Immune Deficiencies

Name of Primary Immune Deficiency: _____

Patient/Applicant Name: _____

Parent/Carer Name (if child under 16): _____

Address: _____

Phone: _____

GP: _____ Immunologist: _____

Date: _____

To whom it may concern:

A Primary Immune Deficiency (PI) is a **genetic condition**, that results in **permanent impairment** of the immune response. The absence of antibodies prevents the **functional capacity** of the immune system from responding to bacteria and viral infections, significantly **impacting quality of life**. It is an **inherited** disorder therefore it is a **permanent condition**. The WHO recognises over 330 diagnosed genetic Primary Immune Deficiency Diseases. PIs form a key group of rare diseases, with some more common than others. As a whole, they represent an important number of people whose lives are **profoundly impacted** by their condition.

_____ suffers from the Primary Immune Deficiency named:

- | | |
|--|---|
| <input type="checkbox"/> Common Variable Immune Deficiency (CVID) | <input type="checkbox"/> Hereditary Angioedema |
| <input type="checkbox"/> Hypogammaglobulinaemia | <input type="checkbox"/> Chronic Granulomatous Disease (CGD) |
| <input type="checkbox"/> X-Linked Agammaglobulinaemia (XLA) | <input type="checkbox"/> Severe Combined Immune Deficiency (SCID) |
| <input type="checkbox"/> Autosomal Recessive Agammaglobulinaemia (ARA) | <input type="checkbox"/> C2 Deficiency |
| <input type="checkbox"/> IgG subclass Deficiency | <input type="checkbox"/> C3 Deficiency |
| <input type="checkbox"/> Specific Antibody Deficiency (SAD) | <input type="checkbox"/> CTLA4 Deficiency |
| <input type="checkbox"/> Selective IgA Deficiency | <input type="checkbox"/> GATA2 Deficiency |
| <input type="checkbox"/> Hyper IgM Syndrome | <input type="checkbox"/> DOCK 8 Deficiency |
| <input type="checkbox"/> CD40 Ligand Deficiency | <input type="checkbox"/> PI3 Kinase Disease |
| <input type="checkbox"/> Ataxia Telangiectasia (AT) | <input type="checkbox"/> Leukocyte Adhesion Deficiency (LAD) |
| <input type="checkbox"/> DiGeorge Syndrome | <input type="checkbox"/> Chediak-Higashi's Syndrome |
| <input type="checkbox"/> Wiskott Aldrich Syndrome (WAS) | <input type="checkbox"/> NEMO Deficiency Syndrome |
| <input type="checkbox"/> Chronic Mucocutaneous Candidiasis | <input type="checkbox"/> Hyper IgE (or Job's) Syndrome (HIES) |
| <input type="checkbox"/> Congenital Neutropenia Syndrome | <input type="checkbox"/> Natural Killer (NK) Cell Deficiency |
| <input type="checkbox"/> Cyclic Neutropenia | <input type="checkbox"/> Mannan Binding Lectin Deficiency (MBL) |
| <input type="checkbox"/> Immunodeficiency with Thymoma (Good Syndrome) | |
| <input type="checkbox"/> Warts, Hypogammaglobulinemia, Infections, and Myelokathexis Syndrome (WHIM) | |
| <input type="checkbox"/> Interferon Gamma, Interleukin 12, and Interleukin 23 Deficiencies | |
| <input type="checkbox"/> _____ | |

More information can be found in the **MEDICAL REPORT** and at <https://www.niaid.nih.gov/diseases-conditions/immunologic-diseases> and **THE IMMUNE DEFICIENCIES FOUNDATION AUSTRALIA** <https://www.idfa.org.au>

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Functionality: This is a **chronic** medical condition which **impacts greatly** on _____'s **quality of life**, especially in the areas of:

- | | |
|---|---|
| <input type="checkbox"/> mobility / fatigue | <input type="checkbox"/> communication |
| <input type="checkbox"/> social interaction | <input type="checkbox"/> education and learning |
| <input type="checkbox"/> self-care | <input type="checkbox"/> self-management |
| <input type="checkbox"/> employment | <input type="checkbox"/> community contribution |
| <input type="checkbox"/> emotional well being | <input type="checkbox"/> psychological well being |

Treatments include Immunoglobulin Replacement Therapy, Haematopoietic Stem Cell Transplant Therapy (Bone Marrow Transplant), immunomodulation, antibiotics and antifungals.

_____ 's treatment includes:

- Immunoglobulin Replacement Therapy** - a blood product made from plasma and listed on the World Health Organisation list of essential medicines as treatment for PID. Treatment is **life-long**.
 - Intravenous immunoglobulin (IVIg) in hospital 2-4 weekly
 - Subcutaneous immunoglobulin (SCIg) at home 1-3 times a week via a pump into the stomach
- Immunomodulation Therapy:**
 - Gamma Interferon A self-administered injection in the arm or thigh 3 times a week. Treatment is **life-long**.
 - _____
- Antibiotics**
 - Prophylactic **antibiotics**
 - Antibiotics prescribed more than 5 times per year**
- Antifungals**
 - Prophylactic **antifungals**
 - Antifungals** prescribed more than 5 times per year
- Haematopoietic Stem Cell Transplant**
 - Successful **Haematopoietic Stem Cell Transplant** Therapy - HSTC (previously a Bone Marrow Transplant)
 - Unsuccessful **Haematopoietic Stem Cell Transplant** Therapy (HSCT) with complication of Graft VS Host Disease.

Because the immune system is compromised, patients with PID also suffer **other diseases** and **permanent autoimmune conditions**.

_____ also has the following conditions:

- | | |
|--|-------------------------------|
| <input type="checkbox"/> Bronchiectasis | Respiratory Physician: _____ |
| <input type="checkbox"/> Pneumonias | Respiratory Physician: _____ |
| <input type="checkbox"/> Bowel disease | Gastroenterologist: _____ |
| <input type="checkbox"/> Gastrointestinal granulomas | Gastroenterologist: _____ |
| <input type="checkbox"/> Liver Abscesses | Physician: _____ |
| <input type="checkbox"/> Rhinitis/Anaphylaxis/Allergies | Immunologist/Allergist: _____ |
| <input type="checkbox"/> Endocrine Disorder | Endocrinologist: _____ |
| <input type="checkbox"/> Granulomas in the Urinary Tract | Urologist: _____ |

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- | | |
|--|-----------------------|
| <input type="checkbox"/> Lymphadenitis | Physician: _____ |
| <input type="checkbox"/> Skin abscesses / Cellulitis | Physician: _____ |
| <input type="checkbox"/> Osteomyelitis | Physician: _____ |
| <input type="checkbox"/> Arthritis | Rheumatologist: _____ |
| <input type="checkbox"/> Lupus | Rheumatologist: _____ |
| <input type="checkbox"/> Neurological Disorder | Neurologist: _____ |
| <input type="checkbox"/> Other | Specialist: _____ |

In addition to treatment listed, _____ **has the following treatment(s)** due to the above **co-morbidities** associated with their primary immune deficiency:

- Antibiotics more than 6 times per year
- Antifungals more than 6 times per year
- Prednisone / Corticosteroids
- Mesalazine/Salofalk
- Infliximab/Rituximab
- Azathioprine
- Thyroxin
- Methotrexate /Hydroxychloroquine (Plaquenil)
- Interferon Gamma
- Itraconazole
- Epilum
- Ventolin / Asthma preventatives
- Nasal spray
- Amitriptyline/ antidepressants
- _____
- _____

Due to the **physical impact** of primary immune deficiency, the **side effects of lifelong disease and treatment** and the **associated co-morbidities**, a large percentage of primary immune deficient patients experience **psychological** and **emotional** conditions **requiring a Psychologist or Psychiatrist**. This frequently **starts at a young age** with diagnosis and the first needle on commencement of immunoglobulin replacement therapy. Some Primary Immune Deficiencies are characterised by skin conditions, children can be **bullied** at school, experience **developmental delays** due to constant infections and this continues throughout life.

_____ suffers from:

- | | |
|--|---|
| <input type="checkbox"/> anxiety | <input type="checkbox"/> needle phobia |
| <input type="checkbox"/> depression | <input type="checkbox"/> germ phobia |
| <input type="checkbox"/> panic attacks | <input type="checkbox"/> fear of getting sick |
| <input type="checkbox"/> obsessive compulsive disorder (OCD) | <input type="checkbox"/> fear of losing their job |
| <input type="checkbox"/> agoraphobia | <input type="checkbox"/> feeling no-one understands their illness |
| <input type="checkbox"/> fear of going out | <input type="checkbox"/> feeling isolated and lonely |
| <input type="checkbox"/> fear of hospitalisation | <input type="checkbox"/> being bullied |
| <input type="checkbox"/> fear of being made fun of | <input type="checkbox"/> fear of being stupid |
| <input type="checkbox"/> not keeping up at school | <input type="checkbox"/> not keeping up at work |
| <input type="checkbox"/> being unable to breathe (for those with lung issues/bronchiectasis) | <input type="checkbox"/> being unable to participate and keep up with physical events at school |

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_____ is currently seeing the following:

Psychologist: _____

Psychiatrist: _____

Other Psychology Therapist: _____

Due to **chronic infections** and **illness** _____

- spends many weeks in hospital per year
- misses many days of school
- misses many days of work
- is unable to work
- is restricted to part time work only
- only able to work part time occasionally
- is unlikely to ever work
- suffers from depression and alienation
- requires carer's intervention and assistance for daily living activities
- requires carer's intervention and assistance with weekly subcutaneous immunoglobulin treatments
- requires carer's intervention and assistance with treatments
- requires permanent ongoing hospitalisation for treatment
- requires carer's intervention and assistance with school work
- requires carer's intervention for daily motivation and focus

_____ 's **current goals** are:

- to spend less days in hospital
- to do my own treatment (subcutaneous infusion at home)
- to be more active and healthy
- to be able to attend school more often
- to be able to attend and complete TAFE/university
- to be able to work
- to increase self-reliance and community participation
- to reduce social isolation and increase participation
- to increase reablement
- _____

*Primary Immune Deficiency is a **genetic disease** that results in **permanent impairment** of the immune response significantly **impacting Quality of Life**.*

_____ receives the following additional support:

Informal support

- care and help from family
- care and help from friends

Community support

practical, educational and emotional support from the Immune Deficiencies Foundation of Australia (IDFA) about primary immune deficiencies www.idfa.org.au

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Other support

Mainstream support

- support from school
- support from GP
- Health care support from Specialist Physicians
- _____
- _____

Other Medical Services

- Physiotherapy
- Speech pathology
- Counselling
- Dietician
- _____
- _____
- _____

Other Services

- _____
- _____
- _____

_____ **needs reasonable and necessary funded supports and services that the NDIS provides.** Without access to these supports and services _____ 's capacity for achieving a basic level of **reablement is removed** and **reduced community participation, integration and increased isolation will continue** into the future.

Kind regards,

_____ OR _____

Patient

Parent / Carer / Parent