

Looking forward: What can we expect in 2023 and beyond



Rohan Greenland, CEO
MS Australia

MS Strategic Planning: A 2022 Recap

- January released 2022-26 Strategic Plan
- First for combined MSA/MSRA organisation
- Combined goals: Research, Advocacy, Cure

A world without MS



Commitment to supercharge MS research

Research Agenda

- Find cures through remyelination and repair
- Support & expand clinical trials for cures and prevention of MS
- Develop better treatments and prevent MS via collaboration and shared infrastructure



Record investment in research this year

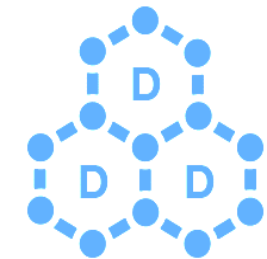
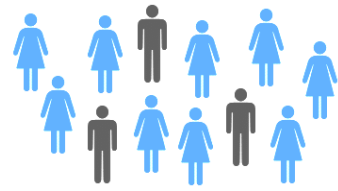
Federal Budget March 2022

- **\$18m** from MRFF for MS research; particularly for EBV
- **\$4m** grant opportunity for a clinical trial that tests nerve repair and protection therapeutics for MS
- **\$20.3m** for Nurses, Allied Health
- **\$37.8m** for International Clinical Trials Collaborations

Record investment by MS Australia in research

- Over \$7M in 2022
 - › **\$6.9M** - Twenty-six new projects
 - › **\$180,000** - Incubator grants and postgraduate scholarship

MS Australia's National Collaborative Platforms



MS Australia Brain Bank

to coordinate the collection, storage and distribution of neurological tissue from people with and without MS for use in research in Australia and across the world

Australian MS Longitudinal Study

to capture the voices directly from people living with MS, now in its 20th year

InforMS

an online MS portal to improve healthcare for people with MS

ANZGene

a major genetics collaboration looking for genes involved in susceptibility and progression of MS

MS Clinical Trial Platform and website

to link people with MS with clinical trials in Australia and New Zealand

Australian MS AHSCT Registry

to link people with MS with clinical trials in Australia and New Zealand

PrevANZ

our clinical trial testing whether vitamin D can prevent MS in those most at risk

International Progressive MS Alliance

- Collaboration driven by 'The Big Five', including MS Australia, to make progressive MS:
 - › a **global research priority** and
 - › **accelerate and improve** testing and approvals for treatments for progressive MS
- IPMSA has invested \$43m to date, growing to \$108m by 2025
- Investing \$5.5m to support the next phase of a collaborative network to further develop promising compounds that target critical disease activities that drive progressive MS and brain injury

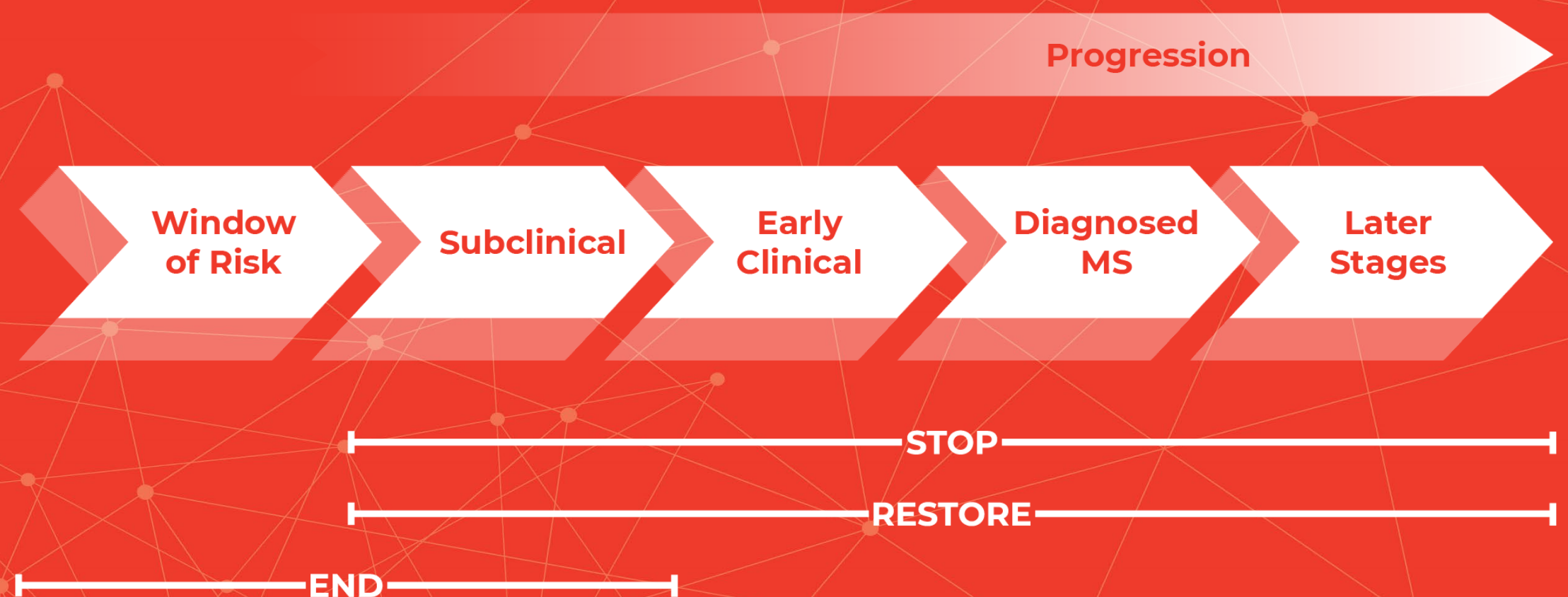
ECTRIMS

- BTK Inhibitors
 - › Four Stage III trials, two in the pipeline
- Smouldering MS
 - › Flipping the Pyramid
- MS Nurses
- Vitamin D Study



Pathways To Cures

- Endorsed by 26 MS organisations worldwide
- Neat fit with MSA research roadmap
- \$20m raised in US by lead donors
- Operational plan in development
 - › Alignment of global resources



Platypus

- Developed a new way of effectively testing new treatments, faster
- Run compounds in parallel and use an adaptive design
- Include biological tracking and testing during the trial “experimental medicine” to learn more about what works and what doesn’t in people with MS
- Include more diversity of participants in trials
- Include people with MS in clinical trial design
 - › Phase 1 – clinical trial readiness
 - › Phase 2 - PLATYPUS



PrevANZ - Vitamin D MS prevention trial

- A world-first clinical trial funded by MS Australia
- People with a first episode of demyelination who were not vitamin D deficient were treated with one of three doses of vitamin D or a placebo.
- Vitamin D at any of the three doses did not prevent the onset of MS in the trial participants
- Results released at ECTRIMS

Recommendations from the MS Nurse Care in Australia Report



Raise awareness of MS Nurses and their benefits

Ensure the value, support and services provided by MS Nurses are escalated throughout the MS community and by other health practitioners.



Assist the existing MS Nurse workforce

Develop a policy, advocate for, and identify delivery mechanisms for ongoing sustainable employment, training, and support of existing MS Nurses in Australia.



Increase the number of MS Nurses

Develop a range of models, including funding arrangements, to allow for the proper identification and support for the expansion of the MS Nurse workforce.



Increase access to MS Nurses

Deploy targeted advocacy to increase access to MS Nurses through expanded telehealth arrangements.



National Disability Insurance Scheme

- MS Australia campaign 'A better NDIS for people living with MS'
- NDIS Review announced
- Case studies showing the economic impact of early and appropriate access to the NDIS
- Improvements to NDIS for people living with MS



Advocates & Lived Experience

- Review of the National Advocates Scheme – workshop 1 December
- Seek expressions of interest for National Advocates - early 2023
- New Lived Experience Expert Panel (LEEP) – early 2023

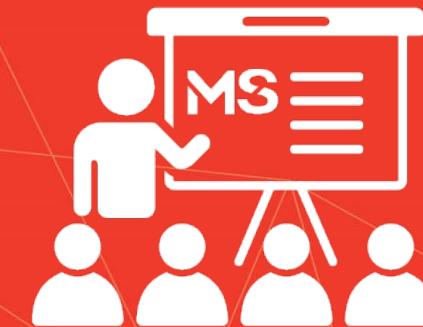


Other Advocacy Opportunities

- Older people with a disability
 - › No change to 65 age limit
 - › Don't receive the same supports in aged care as under the NDIS
 - › Ongoing active engagement in aged care reform
- Support for people who cannot access the NDIS
- Disability Royal Commission
- Parliamentary Friends of MS



HEAR OUR
VOICE



UNDERSTAND
MS



DON'T
DISCRIMINATE

Neurological Alliance Australia

- Alliance of 16 not-for-profit peak organisations
- Opportunity to advocate on a broader scale
- Chair of the NAA
- Neurological reference group within the National Disability Insurance Agency
- Neurological minimum data set overseen by the AIHW



**NEUROLOGICAL
ALLIANCE
AUSTRALIA**



RESEARCH
ADVOCACY
CURE



Thank you

