

BLUE SKY NEWS

ISSUE 79 | JULY 2021 EDITION

EVOLUTION

NEW PHASE II CLINICAL TRIAL

Advocacy

LEAVE NO MAN BEHIND

It's time to review the evidence on PSA Testing

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DONATE FOR DAD THIS FATHER'S DAY

This Father's Day PCFA will be celebrating the contribution of Australian dads to our community.

Email a photo of your father via enquiries@pcfa.org.au and we'll share his story on social media.

To support our life-saving work for Australian men and families, please consider making a donation on Father's Day.



25 YEARS OF RESEARCH AND SUPPORT

Welcome to the July edition of Blue Sky News, a magazine dedicated to you and others who wish to bring an end to prostate cancer. In this edition, we commemorate PCFA's 25th Anniversary, reflecting on past achievements and our future vision of a world free from prostate cancer.

When you turn these pages, you'll learn more about what's ahead for PCFA, and the many ways we will continue to support you and your family with beating prostate cancer.

With your Will, we can end the wait

If prostate cancer has impacted your life, you can safeguard those you love by offering a bequest to PCFA in your Will.

When you decide to fund a bequest today, you will be inspiring future research and nursing services, giving back so that together we can protect our community against prostate cancer and end the wait for a way to beat this disease.

To make your legacy known, call our team today on **1800 22 00 99** and say you'd like to leave a gift in your Will.

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Associate Professor Steve CallisterNational Board Chairman

WATE -

Professor Jeff Dunn AO
Chief Executive Officer



Would you like to confirm your legacy? Please email *donations@pcfa.org.au*

15 NEW NURSES SET TO START: MAKING A DIFFERENCE FOR MEN & FAMILIES

SERVICE IMPACTS CONFIRMED BY HEALTH CARE EXPERTS

REDUCTION IN EMERGENCY **DEPARTMENT VISITS**

REDUCTION IN SPECIALIST CONSULTATION TIMES

REDUCTION IN RATE OF MISSED MEDICAL APPOINTMENTS



15 new PCFA Prostate **Cancer Specialist** Nurses are set to start work soon, allowing us to reach more men and families in need.

The ongoing expansion of our Prostate Cancer Specialist Nursing Service follows the appointment of 25 hospitalbased nurses over the past 12 months, with 87 now on duty nationwide, backed up by our new Telenursing Service, available to everyone in the community.

PCFA's Director of Nursing Programs, Sally Sara, says the service is going from strength to strength.

"It's wonderful to see the difference we're making in people's lives.

"An independent evaluation has found that patients rate the service as having the biggest impact on their overall state of health, wellbeing, confidence, and ability to navigate the health care system. We provide support and care that no other organisation can offer."

15 New Locations

- Genesis Care Southport (QLD)
- Cairns & Hinterland Health Service (QLD)
- Townsville Health Service (QLD)
- Ipswich Hospital (QLD)
- Shoalhaven Cancer Centre (NSW)
- Tamworth Hospital (NSW)
- Camden Region Hospitals (NSW)
- Bega/Moruya Hospitals (NSW)
- Northern NSW Cancer Local Health Network Lismore (NSW)
- Genesis Care Cabrini Hospital (VIC)
- Yorke & Northern Local Health Network (SA)
- Hollywood Private Cancer Centre (WA)
- Sir Charles Gairdner Hospital (WA)
- Royal Hobart Hospital (TAS)
- Genesis Care Mandurah (WA)

✓ To speak to a Prostate Cancer Specialist Nurse, phone 1800 22 00 99



While Australian prostate cancer survival rates are at an all-time high, more than 3,000 men in our community will still die from the disease each year, and we are yet to discover how to stop the disease from spreading.

Metastatic castration-resistant prostate cancer (mCRPC) is the name given to advanced prostate cancer when it stops responding to conventional treatments, such as hormone therapy.

Despite our best efforts to treat mCRPC, median survival time is still unacceptably low, at just 12 to 35 months.

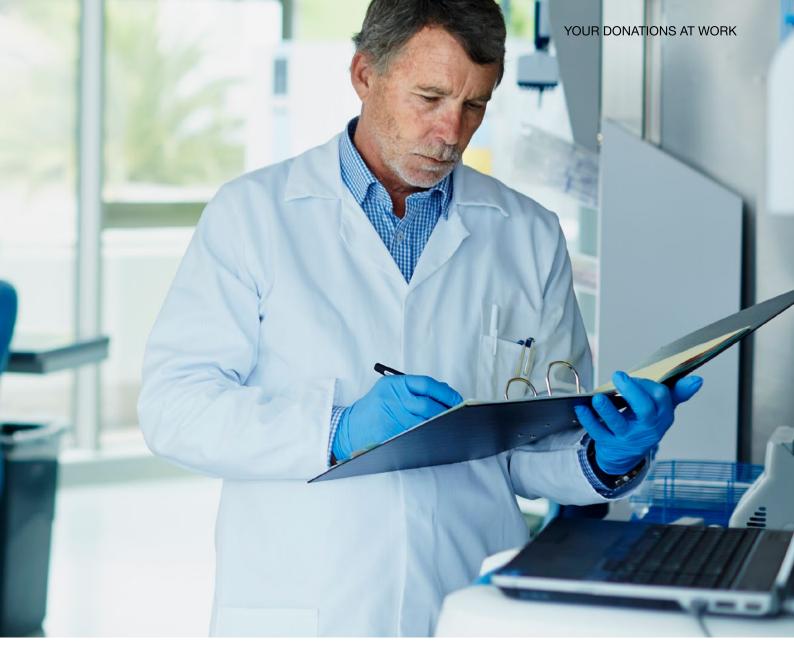
The PCFA ANZUP EVOLUTION Phase II Clinical Trial will study the effectiveness of a new type of treatment, combining Lu-PSMA with immunotherapy, to try and beat mCRPC.

The world-first randomised clinical trial will involve Australia's leading cancer centres and is expected to involve at least 100 patients from around the country.

DETAILS

Full-title: A randomised phase II trial of Radionuclide 177Lu-PSMA Therapy versus 177Lu-PSMA in Combination with ipilimumab and nivolumab for Men with Metastatic Castration Resistant Prostate Cancer (mCRPC).

Aim: To compare outcomes from 177Lu-PSMA given as a single agent with 177Lu-PSMA provided in conjunction with ipilimumab and nivolumab.



Participants: Men with mCRPC who have progressed on novel anti-androgens +/-docetaxel (either in castration sensitive or resistant setting) and have significant PSMA-traceable disease will be recruited to the study in a 2:1 randomisation (67 patients in 177Lu-PSMA and ipilimumab/nivolumab and 33 patients in 177Lu-PSMA alone arm).

Exclusions: Men with prior autoimmune disease will be excluded.

Method: Men allocated to the 177Lu-PSMA alone arm

will receive up to six doses of 177Lu-PSMA given every six weeks. Men allocated to the 177Lu-PSMA and ipilimumab/ nivolumab arm will receive up to six doses of 177Lu-PSMA given every six weeks, in conjunction with four cycles of ipilimumab and nivolumab, followed by maintenance nivolumab alone, for a total of 24 months of treatment.

Measures: 12 months PSA progression free survival.

Participating sites: Cancer centres in Melbourne, Sydney, Brisbane, Perth, and Adelaide

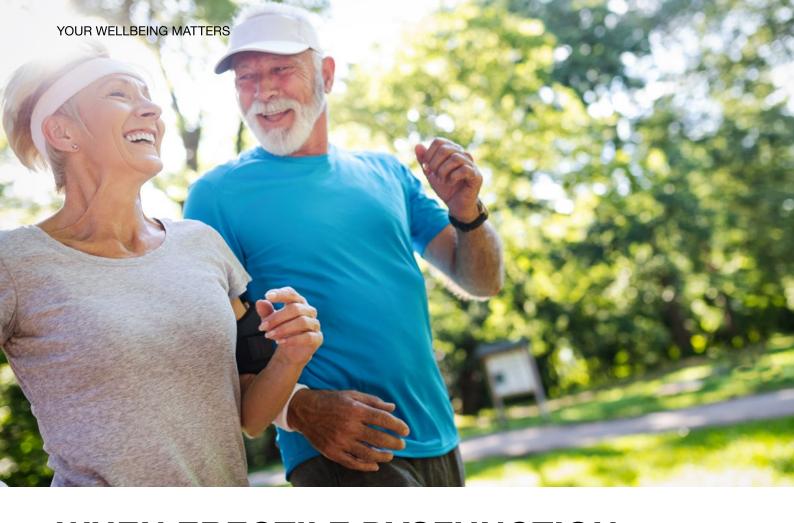
are expected to take part, with the possibility that additional centres may join the trial at a later stage.

Recruitment for the trial is expected to commence later this year.

You can stay updated via our monthly e-news and social media pages.

Email enquiries@ pcfa.org.au





WHEN ERECTILE DYSFUNCTION TABLETS DON'T WORK: WHAT'S NEXT?

While the diagnosis of prostate cancer can be stressful, the treatments prescribed can be equally so.

Often therapeutic benefits are a case of trial and error, where some treatments may work for one person and not for another. Having a multi-disciplinary team is key, together with the support of a counsellor or psychologist.

When all medication-based options (and even mechanical ones, such as vacuum erection devices) have failed: what's next?

One possible answer is an intracavernosal injection, involving the self-administration of a few millilitres of fluid directly into the body of the penis. The medication allows the blood vessels in the penis to dilate, allowing the penis to engorge with blood, thus resulting in an erection.

While there can be side-effects, these injections have been found to be safe and effective and are widely used around the world. In men who have undergone a radical prostatectomy, the success rate of using these injections is as high as 85%. In a study of 683 men using penile self-injections over a six-month period, 87% of the 471 subjects who completed the study were satisfied with results (as were 86% of their partners).

In summary, don't give up trying if the tablets you've been prescribed are not resulting in the erection you or your partner want – alternative options may be available.

Consult a Prostate Cancer Specialist Nurse or call our Telenursing Service on 1800 22 00 99 for more information.

PROSTATE CANCER OUTCOMES REPORT

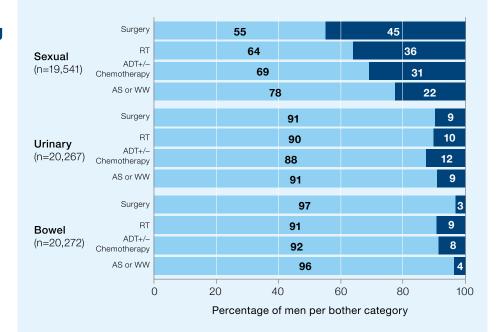
The clinical treatment of prostate cancer in Australia has significantly improved in recent years, proving the value of ongoing research and new standards of care.

At the same time, Australian men with prostate cancer continue to face many challenges. While many aspects of treatment are improving, high numbers of men still experience concern in the days, weeks, and years after their diagnosis.

These findings, from the Prostate Cancer Outcomes Registry of Australia and New Zealand, demonstrate the strong need for PCFA's Prostate Cancer Specialist Nurses and tailored support for men who are navigating life after treatment.

The report found that median age at diagnosis increased slightly, and that the proportion of men with low-risk disease on Active Surveillance increased significantly, in an important move towards eliminating the over-treatment of prostate cancer.

FIGURE 11: Patient-reported bother 12 months after treatment, across PCOR-ANZ, by EPIC-26 domain and treatment type (2015-2018)



None/small Moderate/big

- 'No bother', 'very small bother' and 'small bother' have been combined into one category; 'big bother' and 'moderate bother' have been combined into another.
- 'ADT' was administered without radiation therapy or surgery, but may include chemotherapy; this group also includes a minority of men receiving chemotherapy alone.
- See Supplementary Tables S3 for more information on bother, and S6 for follow-up methodology and quality-of-life completion rates.
- Percentages are rounded and may not add to 100%.
- ADT, androgen-deprivation therapy; AS, active surveillance; EPIC, Expanded Prostate Cancer Index Composite; RT, radiation therapy; WW, watchful waiting.

MEDIAN AGE AT DIAGNOSIS INCREASED SLIGHTLY

2015

2018

67.6
YEARS

68.3 VEARS

MEN WITH LOW-RISK DISEASE ON ACTIVE SURVEILLANCE JUMPED

2015

2018

54%

71%

For the first time, the report found that transperineal biopsies were performed more frequently than other forms of biopsy, which is an important step towards minimising the risks of harm from invasive procedures.

Ieave no man behind IT'S TIME TO REVIEW THE PROPERTY OF THE P

EVIDENCE

It has been five years since the release of Australia's first Clinical Guidelines on PSA Testing, and they are urgently due for an overhaul.

With vast changes to prostate cancer diagnosis and treatment in that time, PCFA has called on the Federal Government to back the creation of a new set of Consumer and Clinical Guidelines to ensure no man gets left behind.

PCFA has highlighted unacceptable gaps in the current guidelines, which may be contributing to late diagnosis and increased risks of death.

"Our research shows around 75% of Australians do not know the guidelines, 70% of men don't know the symptoms of prostate cancer, and 87% of us don't understand prostate cancer stages at diagnosis," says PCFA's CEO, Professor Jeff Dunn AO.

"This is an alarmingly high level of unawareness that delays early detection and diminishes population-wide survival prospects."

Lack of community and individual awareness can make it harder for newly diagnosed men to fully understand their treatment options, resulting in poorer quality of life and survivorship outcomes:



1_{IN} **5**

MEN WITH PROSTATE CANCER WILL DEVELOP ANXIETY AND DEPRESSION **72%**

OF MEN WITH
PROSTATE CANCER
WILL NOT SEEK HELP
FOR DISTRESS

67%

OF MEN WITH
PROSTATE CANCER
HAVE UNMET
INFORMATION NEEDS

70%

INCREASED RISK
OF SUICIDE FACED
BY MEN WITH
PROSTATE CANCER

Australia has one of the highest incidence rates of prostate cancer internationally, with one in every six Australian men likely to be diagnosed during their lifetime.

"While survival rates for prostate cancer are high," Prof Dunn says, "more than 3,000
Australian men still die of the disease each year, and around 17,000 men are newly diagnosed.

"Worryingly, only 36% of Australian men are diagnosed at Stage 1 of the disease, when it is easier to beat, and the mortality rate in regional areas is 24% higher than the Australian average.

"The burden of disease is high, with 82% of men reporting unmet supportive care needs concerning their sexuality and psychological wellbeing in the first year after their diagnosis, as well as issues with navigating the health system.

"Even 10 years after a diagnosis, 35 to 40% of men experience poorer physical and mental quality of life outcomes and lower life satisfaction, with impacts on workforce participation and engagement in community life," he says.

PCFA has asked Minister for Health Greg Hunt to work with us on an updated set of evidence-based consumer and clinical practice guidelines for prostate cancer testing, to ensure awareness and informed decision-making and outline the options available for addressing individual risks.



25 years towards a world free from prostate cancer

This year marks PCFA's 25th Anniversary, a milestone in our ongoing work to improve research, awareness, and support.

Australian support groups for prostate cancer first formed in 1993, with the establishment of Prostates Anonymous, a self-help society for men who had been impacted.

In 1994, when Australian television personality Roger Climpson was treated for prostate cancer, a more organised movement started to take shape. In the weeks following his treatment, Roger discovered that many of his

friends had also been diagnosed, although the information they received was confusing, and support services were lacking.

Roger was also concerned that no groups were raising funds for research to beat the disease.

He called together members of the Rotary Club Lane Cove and in 1996 they formed the Prostate Cancer Research Foundation, which is today known as PCFA.



Pam Russell and Roger Climpson

25 YEARS OF PROGRESS



\$31M

IN RESEARCH FUNDING OVER THE PAST FIVE YEARS

5-YEAR RELATIVE SURVIVAL

1996 **73.5**% 94.5% \$\int \(\)





87

PROSTATE CANCER SPECIALIST NURSES



14,000

SURVIVORSHIP KITS SENT EVERY YEAR



6,000

MEN IN OUR ONLINE COMMUNITY



130

PROSTATE CANCER SUPPORT GROUPS



A NEW NATIONWIDE TELENURSING SERVICE GIVING BACK TO OUR COMMUNITY



GIVING IS LIVING: A FATHER'S LEGACY LIVES ON

"From my family to yours."

Will Austin's father taught him well.

The CEO of leading Australian menswear brand, GAZMAN, prides his business on providing customers with clothing and accessories that are fit for the heroes in our lives – our own families and friends.

Will's father and GAZMAN founder, the late Garry Austin, was a generous family man and a passionate businessman, loved and admired for his kindness.

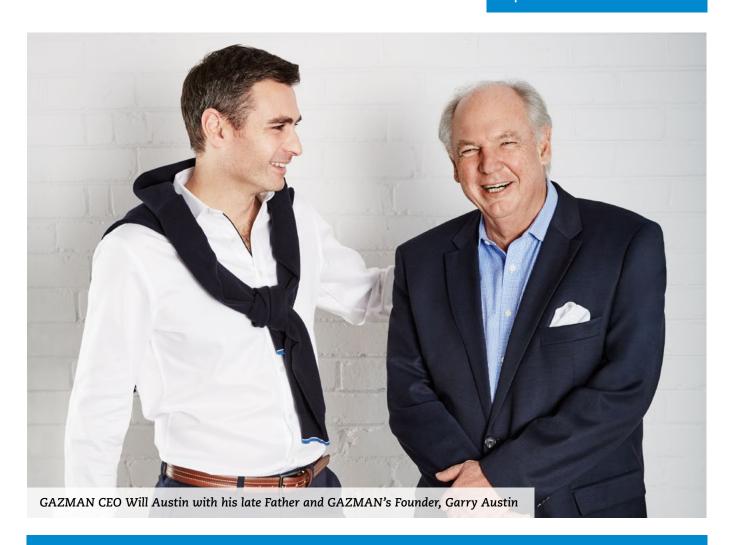
"His determination and passion to succeed were inspiring and he had the ability to foster lasting relationships, enabling GAZMAN to become the brand it is today," Will says.

"I had the privilege of working closely with Dad for 20 years. It is my passion and strong desire to continue his legacy and take the brand forward in his honour and memory."

Following Garry's untimely death from prostate cancer in 2019, Will has grown GAZMAN's support for PCFA, raising over \$335,000 for our work.

This year, Will and his team will be a flagship partner throughout Prostate Cancer Awareness Month in September. We encourage you to get into GAZMAN to say thank you.

GAZMAN will donate \$5 from every pair of pants sold during September to our work.



STARGATE: SURVIVAL GAINS ARE IN OUR SIGHTS

Prostate cancer remains the most common male cancer in Australia, claiming the lives of nine men each day.

Our STARGATE Project is working to save lives.

PCFA's STARGATE Project has revealed significant differences in prostate cancer outcomes for men in different geographic areas of Australia, highlighting the need for significantly increased public funding for research, awareness and support.

Australia's three highest death rates from prostate cancer are in the Queensland Outback, Ballarat, and Darwin, with the three highest rates of diagnosis in the Sutherland area of Sydney, on the Mornington Peninsula in Victoria, and at Mandurah in Western Australia.

"The STARGATE data lays bare the tragic fact that men in regional and rural areas of Australia face a 24% higher than average risk of death. Over recent years we have come a long way to defeating prostate cancer, but we still have a long way to go," says PCFA Chairman, Adjunct A/Prof Steve Callister.

"Over the next 10 years more than 30,000 men will die if no action is taken, a death toll that can be avoided if rates of early detection and access to treatment are improved.

"In some regions, high rates of early diagnosis are not improving survival outcomes, which means access to treatment and other factors are playing a part in avoidable prostate cancer deaths.

"An example is the Murray region in New South Wales, which has the highest rate of Stage I diagnosis in the country, but a death rate that is still 20 per cent higher than the national average," Adjunct A/Prof Callister said.

The project aims to increase individual and community awareness of prostate cancer to help save lives.

RUNNING FROM FEAR: BE WITH US FOR THE LONG RUN

If you can do one thing to support PCFA this year, please register now for The Long Run.

This time last year, Katherine Nikiforos was warming up beside her father's hospital bed to take part in The Long Run.

Her dad Angelos was battling advanced prostate cancer, paralysed by spinal cord compression.

"He was first diagnosed in 2013," Katherine says, "And we weren't going to let him face it alone."

The family immediately became

involved in fundraising for PCFA, hosting barbecues and calling on friends and workmates to help raise awareness and donate for research.

"Supporting PCFA events gave us power in the process, knowing we were raising money that could help save dad's life. It let us channel our energy into positive actions, so that others would have brighter hope of a future without fear of this disease."

Katherine says her dad "experienced the complete physical, emotional, and psychological rollercoaster

that comes with prostate cancer", but never let it get him down.

He passed away on September 26 last year, with his loving wife Toni and daughters Jennifer, Katherine and Michelle by his side.

"He fought so hard, but never stopped smiling. Dad was always optimistic that there would be a new treatment for him to try and that one day there would be a cure."

Katherine raised over \$6,000 in 2020 and has registered for this year's campaign in loving memory of her father, Angelos.

YOUR DONATIONS GO A GREAT DISTANCE

- \$58 Your donation can cover the cost of a PSA Test for a father in a life-saving clinical trial like EVOLUTION.
- \$76 Your donation can cover the cost of a Telenurse to answer the call of a daughter with questions about her dad's diagnosis.
- \$104 Your donation can cover the cost of our advocacy to help fathers and sons access life-saving new treatments, such as LuPSMA.
- \$502 Your donation can help get us closer to our next big research breakthrough, such as the ProPSMA study.



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You can support families like Katherine's by registering at **thelongrun.org.au**



GOVERNOR GENERAL'S MEDALLION: SPECIAL AWARD FOR PCFA NURSING SERVICE

PCFA's Prostate Cancer Specialist Nursing Service has been presented with a Governor-General's Medallion in recognition of its significant contribution to quality cancer care throughout the COVID-19 pandemic. "Linda and I are proud to be associated with organisations like the Prostate Cancer Foundation of Australia. The contribution that the Prostate Cancer Foundation of Australia makes in our community is considerable. We would like to thank you for your work, passion and commitment," His Excellency says.

A GIFT FOR YOU

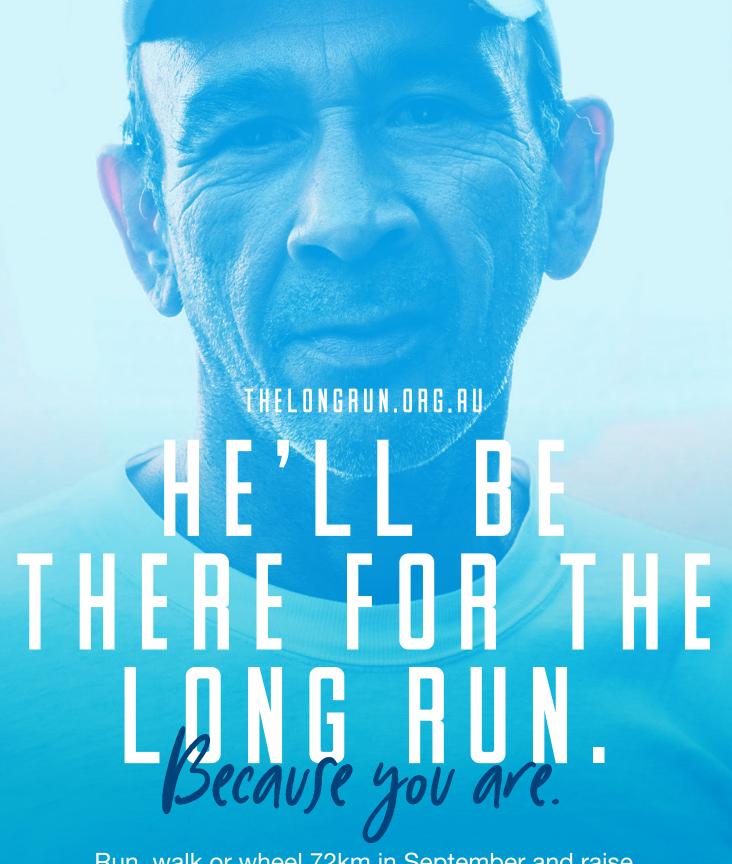
This Father's Day send a gift from PCFA's Interflora Father's Day Collection.

With a range of hampers to choose from, 5% of all purchases will be donated to our mission. Simply enter the coupon code **PCFA15** when you order online and get \$15 off orders over \$100 (including delivery).



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Go to interflora.com.au/occasions/pcfa



Run, walk or wheel 72km in September and raise funds to support men with prostate cancer.

HELP LOVE GO THE DISTANCE. SIGN UP NOW.

