Wilms Cancer Foundation Invited to Help Shape Federal Kidney Cancer Research Funding Through the CDMRP

Organisational participation will give WCF an influential voice in evaluating research proposals and representing childhood kidney cancer priorities within a leading U.S. federal research programme

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FOR IMMEDIATE RELEASE

The **Wilms Cancer Foundation (WCF)** is honoured to announce that it has been invited, as an organisation, to participate in the consumer-review process supporting the **Kidney Cancer Research Program (KCRP)** within the U.S. **Congressionally Directed Medical Research Programs (CDMRP)**.

The invitation, communicated through **General Dynamics Information Technology (GDIT)** in connection with its support for the CDMRP peer-review process, recognises WCF as a participating consumer advocacy organisation representing the childhood kidney cancer community.

WCF will participate through its designated organisational representative, who will undertake the formal responsibilities assigned to a consumer reviewer on behalf of the Foundation. This structure gives WCF an organisational voice within the review process while ensuring that the experiences and priorities of children with Wilms tumor, survivors and families are represented during the evaluation of kidney cancer research proposals.

A Direct Organisational Voice in Research Funding

The invitation represents an important advancement in WCF's research and advocacy work.

Rather than participating only after research has been funded or published, the Foundation will have an opportunity to contribute at the stage when proposed research is being evaluated.

The person designated to represent WCF will participate in the formal review role on behalf of the Foundation and the childhood kidney cancer community it serves. Their contribution will be informed by WCF's organisational experience, international programmes and engagement with children, survivors, parents, caregivers, healthcare professionals and research partners.

This will enable WCF's institutional perspective to contribute directly to the assessment of:

- The potential impact of proposed kidney cancer research
- The relevance of the research to patients and families
- Whether a proposal addresses an important unmet need
- The practical benefits and burdens associated with a study
- Potential improvements in diagnosis and treatment
- Quality-of-life and survivorship outcomes
- The urgency of the problem being investigated
- Whether proposed outcomes are meaningful to patients
- The potential for research to improve clinical practice
- The needs of underrepresented kidney cancer populations

No single organisation or reviewer independently controls federal funding decisions. However, the CDMRP gives designated consumer representatives full voting status within its review panels, allowing participating advocacy organisations such as WCF to contribute meaningfully to the evaluations that inform research funding recommendations.

An Influential Position for WCF

WCF's organisational participation will place the Foundation's perspective directly within discussions involving scientists, clinicians, research leaders and other advocacy representatives evaluating kidney cancer research proposals.

This creates an opportunity for WCF to influence how research applications are assessed at a level where scientific merit, patient relevance, programme priorities and potential impact are considered together.

"This invitation is significant because it has been extended to the Wilms Cancer Foundation as an organisation," said **TJ Hodgkinson, Founder and CEO of the Wilms Cancer Foundation**.

"WCF will participate through a designated representative, but the perspective brought into the review process will be that of the Foundation and the childhood kidney cancer community we serve. It will be informed by our work with children, survivors, parents, caregivers, healthcare professionals and international partner organisations."

"This gives WCF an organisational voice at the stage when research proposals are being evaluated and funding recommendations are being developed. It provides a meaningful opportunity to ensure that Wilms tumor, childhood kidney cancer and long-term survivorship priorities are represented within high-level kidney cancer research discussions."

"Scientific excellence must remain at the centre of research review. However, the people and organisations that understand the consequences of cancer bring another essential form of expertise. They understand the realities of diagnosis, treatment, family disruption and the health challenges that may continue long after treatment has ended."

Organisational Representation Within the Review Process

The invitation has been extended to the **Wilms Cancer Foundation as a consumer advocacy organisation**, rather than simply to an individual acting in a personal capacity.

The Foundation will appoint or nominate a designated representative to undertake the individual responsibilities required by the review process. That person will participate on behalf of WCF and bring the Foundation's collective experience, priorities and advocacy perspective into panel discussions.

Within the CDMRP model, consumer representatives participate alongside scientists and clinicians as full voting panel members. This allows WCF's organisational perspective to contribute directly to the evaluation and scoring of research proposals.

Although a formal panel vote must be exercised by an individual reviewer, that individual will serve as the **designated representative of WCF** rather than solely in a personal capacity.

This distinction is important. The influence of the position is derived not only from one person's lived experience, but from the wider knowledge and international perspective developed through WCF's work with the childhood kidney cancer community.

Representing Childhood Kidney Cancer at a High Level

Wilms tumor, also known as nephroblastoma, is the most common kidney cancer diagnosed in children. Its biology, treatment pathway and long-term consequences differ significantly from the adult renal cancers that account for most kidney cancer diagnoses.

Children with Wilms tumor may undergo:

- Removal of the affected kidney
- Intensive chemotherapy
- Abdominal or whole-lung radiation therapy
- Treatment for metastatic disease
- Multiple treatment regimens following relapse
- Stem-cell transplantation in some relapsed or high-risk cases
- Years of surveillance and long-term follow-up

Although many children can be successfully treated, some experience relapsed or treatment-resistant disease. Survivors may also face lifelong health consequences involving kidney function, cardiovascular and lung health, growth, fertility, hormonal development, emotional wellbeing and the risk of subsequent cancers.

The comparatively small number of children diagnosed with Wilms tumor can make it difficult for childhood kidney cancer priorities to achieve visibility within the broader kidney cancer research environment.

WCF's participation will help ensure that pediatric kidney cancer is represented when proposed research has potential relevance to tumor biology, genetics, imaging, surgery, drug development, treatment toxicity or survivorship.

Helping Steer Research Towards Patient Priorities

Scientists and clinicians bring essential knowledge of research methods, tumor biology, medicine and clinical practice. Consumer advocacy organisations contribute a complementary form of expertise grounded in patient and family experience.

Together, these perspectives help determine whether a proposal is both scientifically credible and capable of producing meaningful benefits.

WCF will use its organisational participation to encourage appropriate attention to priorities including:

- Earlier and more accurate diagnosis
- Better understanding of Wilms tumor biology
- New treatments for relapsed and high-risk disease
- Safer and less toxic treatment approaches
- Precision medicine and molecularly informed treatment
- Reduced chemotherapy- and radiation-related effects
- Kidney preservation and long-term renal health
- Fertility preservation
- Psychological and family support
- Survivorship and long-term follow-up
- Improved quality of life during and after treatment
- Greater inclusion of pediatric and rare kidney cancers
- More equitable access to research and treatment

The Foundation will also bring forward the concerns of parents and caregivers who must make complex treatment decisions while supporting children through difficult and sometimes prolonged periods of care.

How the CDMRP Review Process Works

The CDMRP uses a two-tier review process designed to balance scientific excellence with programme relevance and potential patient impact.

Scientific Peer Review

Scientific peer review evaluates each application according to published scientific, technical and impact criteria.

Applications are generally assigned to scientific reviewers and a consumer representative. Reviewers provide written evaluations, preliminary scores and contributions to panel deliberations.

WCF's designated representative will undertake the consumer-review responsibilities on behalf of the Foundation, bringing the organisation's childhood kidney cancer perspective into this stage of the assessment.

Programmatic Review

Programmatic review follows scientific peer review.

At this stage, favourably reviewed applications are compared against one another and considered in relation to:

- The mission and objectives of the research programme
- Potential impact
- Programme priorities
- Research portfolio balance
- The intent of the funding opportunity
- The needs of the affected community

The Programmatic Panel develops funding recommendations across a broader portfolio of research.

An application must be favourably reviewed through both tiers to be eligible for funding. Final recommendations remain subject to federal review and approval and the availability of congressionally appropriated funds.

Full Voting Participation

The CDMRP confirms that consumer representatives participate in both peer and programmatic review and sit alongside scientists and clinicians as full voting members.

This means that WCF's organisational participation will be substantive rather than observational.

Through its designated representative, the Foundation's perspective can become part of the formal evaluation used to:

- Assess individual research applications
- Identify strengths and weaknesses
- Consider potential patient impact
- Score proposals against published criteria
- Compare research priorities
- Inform programme-level funding recommendations

The final authority to approve and award federal funding does not rest with WCF, GDIT or any individual panel member. Nevertheless, the Foundation will have a direct and influential role within the review process that helps determine which proposals are considered scientifically strong, relevant and potentially impactful.

Connecting Research Funding with Lived Experience

The CDMRP model recognises that patients, survivors, caregivers and advocacy organisations possess expertise that cannot be gained exclusively through laboratory or clinical work.

Families understand:

- What it means to receive a life-changing diagnosis
- The physical and emotional burden of treatment
- The difficulty of balancing potential benefits against serious risks
- The long-term consequences of cancer therapy
- The effect of childhood cancer on parents and siblings
- The importance of accessible and understandable information
- The urgency of developing better options for relapsed disease
- The need to consider quality of life as well as survival

Including these perspectives can help reviewers distinguish between research that is scientifically interesting and research that also has the potential to make a meaningful difference to patients and families.

Strengthening WCF's Research Leadership

Participation in the CDMRP review process will strengthen WCF's position as an international childhood kidney cancer organisation connecting patient experience, research, education and advocacy.

It will complement the Foundation's existing initiatives:

- **Global Wilms Tumor Initiative™**
- **Wilms Tumor Knowledge Index™**
- **Wilms Tumor WebApp**
- **Wilms Tumor AI Support Service**
- **Global Educational Library**
- **Complete Guide to Wilms Tumor**
- Multilingual educational literature
- Healthcare professional resources
- Research identification and communication
- Survivorship and long-term care education
- International institutional partnerships
- Global childhood kidney cancer advocacy

The experience will provide WCF with a deeper understanding of emerging research themes and the standards used to evaluate potentially high-impact kidney cancer research.

Confidential information concerning individual applications, applicants and review discussions will remain protected in accordance with all applicable CDMRP and federal requirements.

Advancing Patient-Informed Research

WCF believes that people and organisations affected by disease should have meaningful opportunities to contribute to decisions about research intended to benefit their communities.

Patient and organisational involvement should extend beyond participation in clinical trials. Advocacy organisations can also contribute to:

- Identifying unmet needs
- Establishing research priorities
- Reviewing potential patient impact
- Assessing study burdens
- Evaluating meaningful outcomes
- Communicating research findings
- Supporting future implementation in patient care

The invitation reflects a wider recognition that the strongest research systems combine scientific expertise with patient, caregiver and advocacy experience.

For WCF, the position provides a significant opportunity to help steer research assessment and funding recommendations towards projects capable of delivering genuine improvements for people affected by kidney cancer.

About General Dynamics Information Technology

General Dynamics Information Technology is a technology and professional-services organisation supporting government agencies across areas including health, science, technology and programme delivery.

GDIT supports the first tier of the CDMRP review system, through which scientific, clinical and consumer representatives assess individual research applications against published scientific, technical and impact criteria.

Website: **gdit.com**

About the Congressionally Directed Medical Research Programs

The **Congressionally Directed Medical Research Programs** administers biomedical research funding appropriated by the United States Congress across a range of cancers, diseases, injuries and health conditions.

Its two-tier review process brings together scientists, clinicians, consumer advocacy representatives, members of the military and other specialists to evaluate scientific merit, programme relevance and potential impact.

Website: **cdmrp.health.mil**

About the Kidney Cancer Research Program

The **Kidney Cancer Research Program** forms part of the U.S. Congressionally Directed Medical Research Programs. Its vision is to eliminate kidney cancer through collaboration and discovery.

The programme supports rigorous, innovative and high-impact research intended to benefit Service members, veterans and the American public.

Website: **cdmrp.health.mil/kcrp**

About the Wilms Cancer Foundation

The **Wilms Cancer Foundation** is an international childhood kidney cancer organisation dedicated to improving awareness, education, support, research communication and global collaboration for children and families affected by Wilms tumor.

Through the **Global Wilms Tumor Initiative™** and its international programmes, WCF works to expand access to trusted information, strengthen patient and caregiver education, support healthcare professional engagement and address inequalities in childhood kidney cancer outcomes worldwide.

Website: www.WilmsFoundation.org

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