RETINA RESEARCH FOUNDATION
NEWSLETTER
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AMD Is A Common Chronic Condition

Take a look at the diagram of the 10 most common chronic conditions for adults 65 or older as compiled by the National Council on Aging. A very significant condition is not included – age-related macular degeneration (AMD). Estimates of individuals 65 + with some form of AMD range from 18 to 19.8 million. In the U.S., by age 75, roughly one in three people will develop some form of AMD. These figures place AMD into the list just after Arthritis and before Ischemic / Chronic Heart Disease. Individuals with a sight threatening form of AMD represent just under 2% of all those afflicted, but the progression to more late-stage and serious forms of the disease can happen very rapidly, and it is irreversible and incurable. As the U.S. population ages, these figures will increase and regrettably, people even younger than 65 suffer from macular degeneration as well.

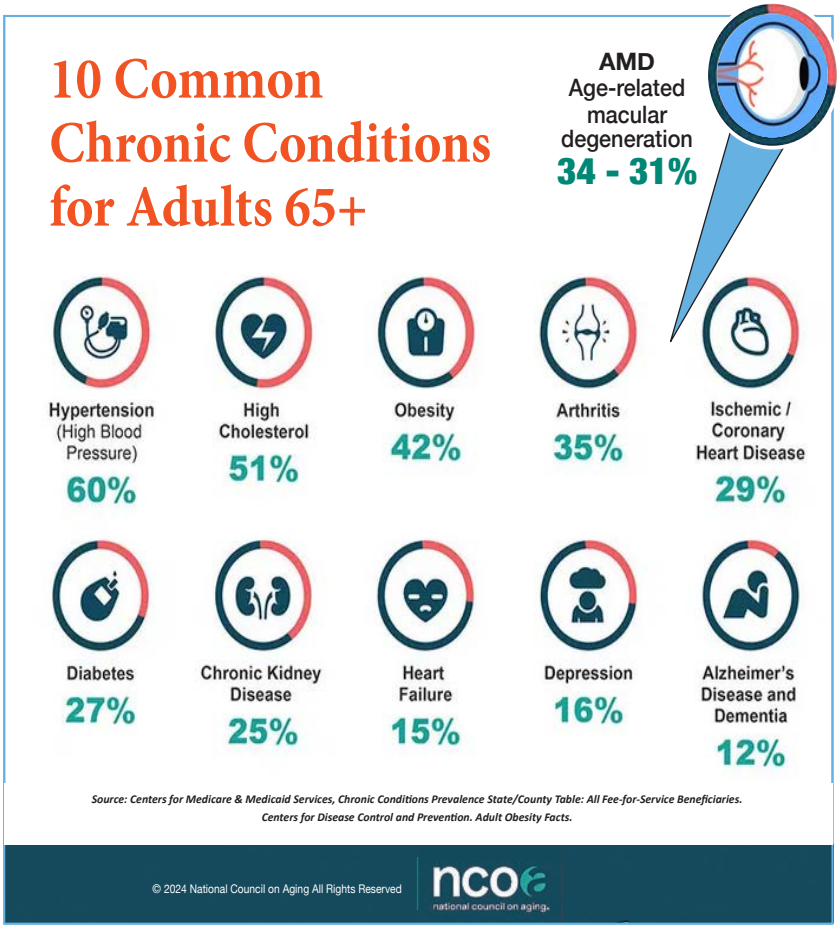
Researchers are working on ways to expand early treatment and detection to improve patient monitoring and outcomes, and to enhance the quality of life for people affected by AMD by reducing the treatment burden and forestalling disease progression.

For more than a decade, ophthalmologists have treated wet AMD with periodic anti-VEGF injections and dry AMD with antioxidant vitamins. These treatments were groundbreaking when introduced, offering hope that this sight-threatening disease could be slowed, and in some cases stopped or even reversed. The anti-VEGF injections block the growth of new, abnormal blood vessels, but many patients experience side effects or treatment resistance over time, and the periodic need for injections presents scheduling challenges that decrease compliance.

RRF funds numerous pilot grant researchers looking for the next generation of AMD treatments, including the research of four new pilot project grantees funded in 2025.

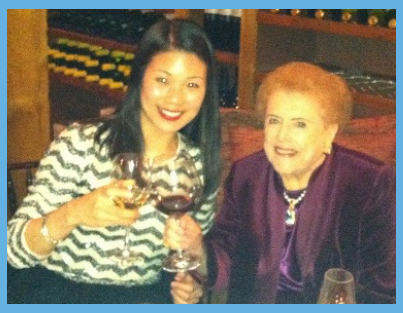
Research over decades is beginning to pay off with new treatments for both forms of AMD on the horizon and, simultaneously, physician tools for managing a patient's disease are also advancing.

Researchers are looking for ways to reduce the treatment burden, and simultaneously, closely monitor the progression of the disease. Today, physicians and patients are more comfortable with telemedicine as a way to stay in contact between in-office visits, and advancements in optical coherence tomography (OCT) technology, a vital tool in managing wet AMD, have allowed the development of home-based OCT systems that patients can turn to between visits.



Alice R. McPherson Retina Research Foundation Chair Named at Baylor College of Medicine

Christina Y. Weng, MD, MBA



Dr. Weng and Dr. McPherson, 2014 Holiday Gathering

Dr. Weng with Dr. McPherson and former BCM fellows, *from left*, Dr. Petros Carvounis, Dr. Brian Lehpamer, Dr. Nora Khatib

Christina Y. Weng, MD, MBA, Professor in the Department of Ophthalmology at Baylor College of Medicine (BCM) in Houston, Texas, has been appointed to the Alice R. McPherson Retina Research Foundation Chair. The Chair was established in 1998, and RRF is most pleased that Dr. Weng has been selected for this distinction in recognition of her clinical expertise, exemplary scholarship and national leadership in ophthalmology.

Dr. Weng serves as the Vitreoretinal Diseases & Surgery Fellowship Program Director at BCM and is a prior recipient of the Dan B. Jones Teaching Award for excellence in resident education. Additionally, she has a faculty appointment at the Level I trauma center, Ben Taub General Hospital, in Houston.

Dr. Weng graduated cum laude from Northwestern University, and obtained her medical degree from the University of Michigan, where she was elected to the Alpha Omega Alpha (AOA) Medical Society. While in Ann Arbor, she also pursued an MBA degree from the University of Michigan's Ross School of Business, graduating with high distinction. Dr. Weng completed her ophthalmology residency at the Wilmer Eye Institute at Johns Hopkins University in Baltimore, and her surgical retina fellowship at the Bascom Palmer Eye Institute at the University of Miami.

Dr. Weng is an active investigator in clinical trials, including the DRCR Retina Network trials and the AGTC Phase 1/2 intravitreal gene therapy study for X-linked retinoschisis. She leads numerous research studies in her areas of interest: macular degeneration, diabetic eye disease, healthcare economics, and telemedicine, including home-based optical coherence tomography (OCT). Dr. Weng is the national protocol chair of the global NIH/NEI sponsored DRCR Retina Network clinical trial evaluating the use of home OCT, a portable version of a physician office-based device used to guide treatment for wet AMD.

Dr. Weng has authored over 150 peer-reviewed publications and dozens of book chapters, and delivered hundreds of national and international lectures around the world. She is the co-editor of the book Women in Ophthalmology: A Comprehensive Guide for Career and Life. Dr. Weng is nationally renowned, holding numerous leadership roles within major ophthalmology organizations such as the American Society of Retina Specialists (ASRS), Retina Society, Macula Society, American Academy of Ophthalmology (AAO), and Women in Ophthalmology.

"It is an incredible honor to be bestowed the Alice R. McPherson Retina Research Foundation Chair in Ophthalmology at Baylor College of Medicine. Dr. McPherson was a true trailblazer in ophthalmology and surgical retina, and her incredible contributions to our field have impacted and bettered the lives of countless patients. I hope that my research, which aims to improve vision and prevent blindness in patients suffering from retinal diseases like macular degeneration and diabetic retinopathy, will continue to do the same. I would also like to express my gratitude to the Retina Research Foundation, founded by Dr. McPherson over half a century ago, which has become one of the world's leading ophthalmic research organizations funding over 1,000 basic research grants and playing a significant role in launching the careers of numerous vision researchers. Dr. McPherson is someone I admired in every way, and it is a true privilege to carry on her legacy through her named Chair."

Home Monitoring for Eye Disease: Has Its Time Finally Arrived?

The promise of monitoring eye disease at home, between ophthalmology visits, is closer to being realized than ever before. There are tools, including phone-based tools that measure changes in visual acuity and have been available for the last decade, but a newly approved AI-assisted imaging device might be a game changer.

A decade ago, a prospective study demonstrated that elderly patients with wet AMD and Diabetes Related Macular Edema (DME) were willing and able to comply with daily self-testing using their mobile device, which stimulated the development of smartphone applications for at-home vision tests. One smartphone application, tests shape-discrimination hyperacuity. A second application, examines a larger central visual field. Both applications are FDA approved for prescription use only. A quick search of available apps on your phone will return numerous options for consideration.

There is also a mobile application (app: OdySight) available by prescription only, which has FDA medical device approval. This app addresses compliance issues by incorporating a puzzle game, along with a monocular vision test, including near visual acuity, contrast sensitivity, and a digital Amsler grid. Test results are sent via a secure server to an online dashboard that can be accessed online by the physician. Any vision decline triggers alerts sent to both the patient and physician. Results from a prospective study demonstrated good agreement between the near visual acuity and Amsler grid modules of OdySight compared with current standards. The application remains under investigation and might offer additional benefits after implementation of new device technology to ensure the tests are performed at a standardized distance and with adequate ambient light.

Taking the technology a step further, a physician-order required devise (Foresee Home) was also approved a decade ago for detecting conversion of intermediate dry AMD to neovascular age-related macular degeneration (nAMD), wet AMD – the more serious form. The device allows patients to perform hyperacuity testing at home with data transferred through telemedicine to a data monitoring center. In a large, prospective randomized clinical trial, use of this device resulted in earlier detection of nAMD, with better visual acuity at the time of conversion compared to Amsler grid self monitoring. To date, factors limiting the adoption of the devise include patient challenges in using the devise consistantly, insurance reimbursement, and the sheer volume of analysis required by physicians. That being said, a retrospective review of data from over 8,900 patients did show real-world monitoring with the Foresee Home device to be comparable to that seen in clinical trials, which is encouraging as often clinical trial data does not translate to real-world use.

In May 2024, a new imaging technology received FDA approval -- a patient-operated home OCT device, which is enhanced with an AI-grading of the self-administered images. This approach of taking and assessing digital images addresses concerns with earlier acuity testing technology and provides the potential to impact and transform patient care. Approved for treatment for wet AMD, this is the first-ever approval of an AI algorithm for OCT imaging. Patients can quickly take images on a daily basis at home, and the AI-assisted analytics evaluate changes in the images

(continued on page 4)

Daily scanning for disease progression can be performed using Foresee Home. Image courtesy of Notal Vision

(continued from page 3)

and notify the patient's retina specialist of changes. In one pivotal clinical trial, 97% of participating patients, were able to successfully take usable self-images, in, on average, 48 seconds, and stick with it, taking 5.9 scans/week.

Newer technologies combines home-monitoring with AI-enabled grading. Scanly image courtesy of Notal Vision

The advent of at home OCT monitoring for AMD has the real potential to vastly increase efforts to manage AMD and personalize care. Not only does the technology reduce the patient burden of treatment visits to a physician's office, the daily data it provides to physicians transforms patient monitoring and care over time. AI-assisted data analytics can provide early insights into disease activity, facilitating individualized treatment plans with the potential to improve long-term visual outcomes. The caveat is that studies on clinical outcomes associated with the use of home OCT-based treatment protocols are as of yet, limited to small number of patients so definitive measurement of improved outcomes from using the device is still unknown. The goal of a DRCR Retina Network Protocol trial evaluating home OTC that began in 2023 and currently is recruiting patients, is to determine if home OCT guided treatment results in better visual acuity outcomes and fewer treatment injections over time.

If you have been diagnosed with AMD, ask your physician if he or she has experience with any of these technology tools, and whether or not you might be a good candidate and benefit from home-monitoring or participation in a clinical trial.

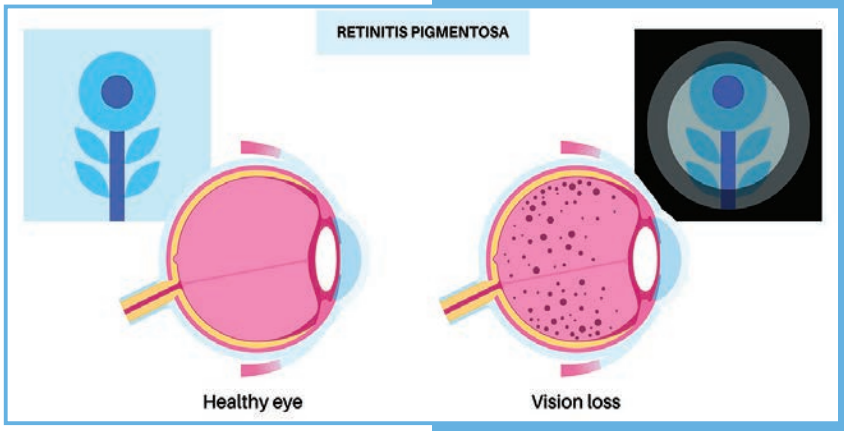
Sources: Retina Today, Jan/Feb 2022, At-Home Monitoring Tools For Today and Tomorrow; The Ophthalmologist, Apr 2025, OCT Closer to Home

RRF Scientific Advisor Researches Inherited Retinal Diseases

Dr. John Chancellor, MD, MS, Department of Ophthalmology, Baylor College of Medicine, Houston, TX

Dr. John R. Chancellor joined the RRF scientific advisory board in 2022. He came to Houston, Texas, to complete his fellowship training at Baylor College of Medicine (BCM) in vitreoretinal diseases and surgery and subsequently, accepted an associate professor position at BCM. Dr. Chancellor received his medical degree from the University of Massachusetts Medical School and completed his residency at the University of Arkansas for Medical Sciences. He also earned a Master of Science degree in Neuroscience & Behavior at the University of Massachusetts Amherst. His clinical and surgical interests include age-related macular degeneration, diabetic retinopathy, and retinal detachment repair. His research interests include surgical outcomes in diabetic retinopathy and inherited retinal diseases.

Dr. Chancellor is an avid researcher in the field of inherited retinal dystrophies. Numerous inherited retinal diseases (IRDs) such as Retinitis Pigmentosa (RP) are targets for gene therapies in development, and Dr. Chancellor is currently a principle investigator (PI) on two gene therapy trials that are actively recruiting and treating patients diagnosed with this disease, which has multiple genetic causes.



One clinical trial Dr. Chancellor is involved with is intended to treat patients with X-Linked Retinitis Pigmentosa, caused by a defect in the RPGR gene. Patients with this condition lack healthy copies of the RPGR gene. It affects about one in 15,000 people in the U.S., making it one of the most common causes of retinitis pigmentosa. Patients are exclusively male, due to the X-Linked nature of the condition. The therapeutic agent, AGTC-501, which is a recombinant adeno-associated virus (AAV) vector, carries a human codon optimized RPGR-open reading frame Exon 15 gene. This study agent is administered in the operating room via a pars plana vitrectomy and subretinal injection. This mechanism and treatment is similar to the process used to administer voretigene neparvovec-rzyl (Luxturna), the only current FDA-approved gene therapy product for an inherited retinal dystrophy. This study is actively recruiting patients between ages 12-50 for treatment with AGTC-501 in a phase 2/3 clinical trial at BCM, with several patients already enrolled. BCM is one of 21 U.S. locations participating in this multi-center study that is also being researched in Australia and the United Kingdom.

The second clinical trial is intended to treat patients with Retinitis Pigmentosa 11 (RP11). This condition is caused by mutations in the PRPF31 gene and affects approximately one in 100,000 people worldwide. In RP11, one copy of PRPF31 is mutated and not producing sufficient protein. The emerging therapy uses small interfering RNA (siRNA) to inhibit production of mutated copies of PRPF31. The gene therapy product, known as VP-001, works by targeting an upstream regulator protein known as CNOT3. This results in increased production of normal copies of PRPF31 protein. VP-001 is administered by intravitreal injection in clinic. The trial has shown positive results in phase 1/2 and will begin phase 3 at multiple locations in the U.S., including BCM in 2025.

For more information on clinical trials for retinitis pigmentosa and many other diseases, and to learn more about eligibility requirements and who to contact in your area, visit clinicaltrials.gov.

Announcing New 2025 RRF Pilot Study Research Grants

Six vision scientists are receiving RRF funding for the first time in 2025:

Oleg Alekseev, MD, PhD,
Duke University School of Medicine, Department of Ophthalmology;

Development of gene supplementation therapy for PROMI associated inherited retinal degenerations

Wei Li, PhD,
Baylor College of Medicine,
Department of Ophthalmology;

Identifying a receptor for disease - targeted anti-angiogenic therapy for Wet AMD

Erika T. Camacho, PhD, University of Texas at San Antonio, Departments of Neuroscience, Developmental and Regenerative Biology;

Modeling the role of 6-phosphofructo-2-kindse/fructose 2, 6 bisphosphatase 2 in retinal metabolism and retinal degenerative diseases

Patricia R. Taylor, PhD,
Case Western Reserve University, Department of Ophthalmology and Vision Science;

The impact of BRD4 on the development of diabetic retinopathy

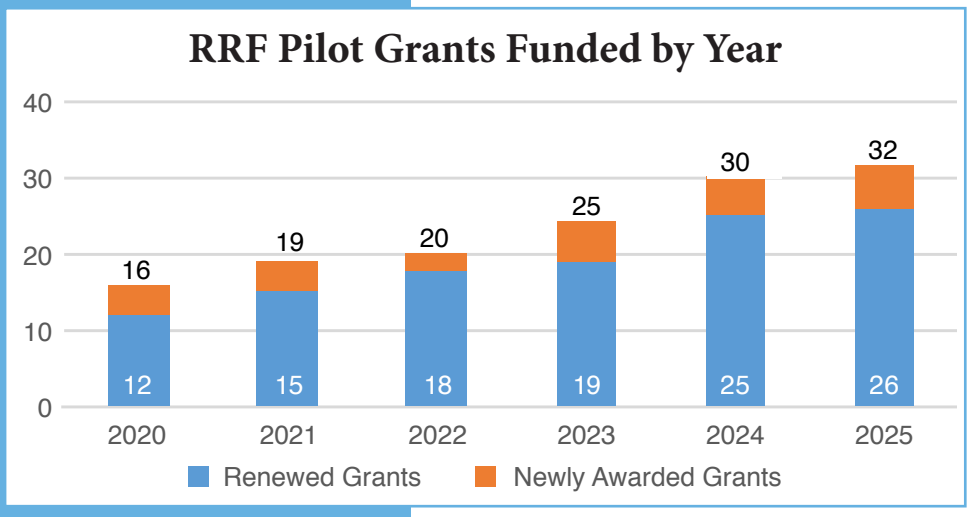
Yuqing Huo, MD, PhD,
Baylor College of Medicine, Department of Ophthalmology;

AMD and subretinal fibrosis

Elizabeth Vargis, PhD,
Utah State University, Department of Biological Engineering;

Analyzing the relationship between Brunch's membrane and AMD progression.

The pilot study grants support experimental, basic science projects designed to investigate previously unstudied or understudied lines of inquiry into the causes of retinal diseases with the goal of obtaining new understanding and advancing scientific knowledge. The ideal outcome is that these studies generate significant novel scientific findings that warrant further investigation and lead to future ongoing projects. The ultimate goal is to develop new therapies for treating vision loss from retinal diseases.



RRF commits to funding pilot study projects for up to three years if progress is demonstrated and RRF funding sources allow. Twenty-six projects were renewed for another year's funding in 2025 for a total of 32 pilot study grants, the greatest number of awards granted in recent years. Visit retinaresearchfnd.org to learn more about the innovative vision research these scientists are conducting.

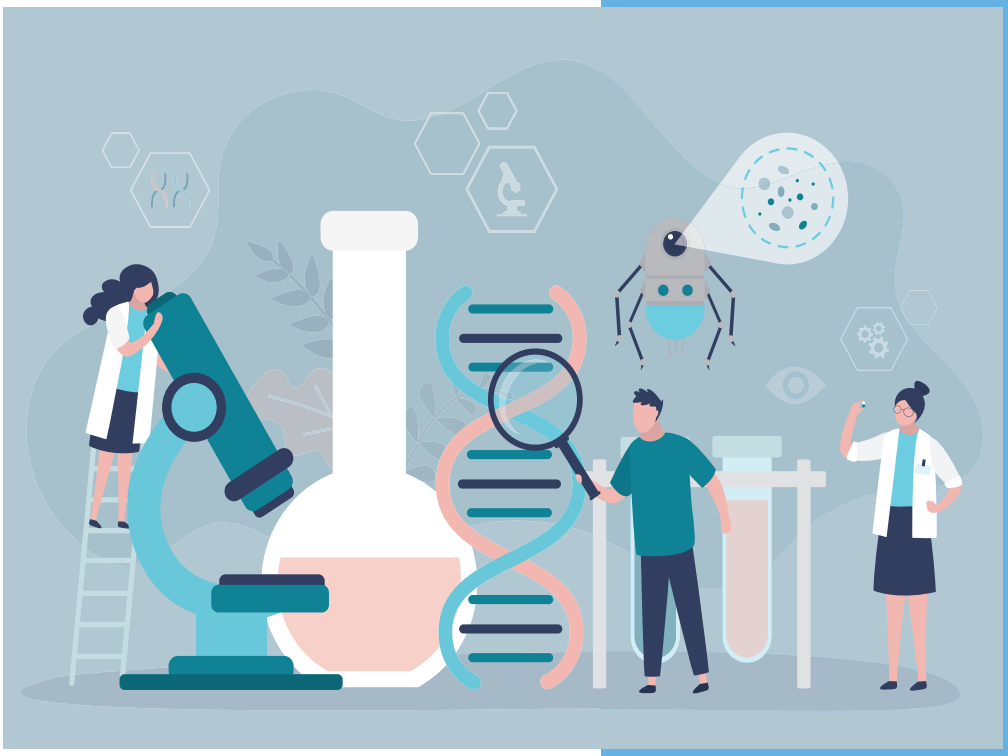
Funding BASIC Science Research: Contributing to the Discovery of Tomorrow's Innovative Treatments

Each year, a large portion, nearly 60% in 2025, of RRF's research funding goes to the pilot study grant program – to basic science research. So much focus is placed upon basic research because these vision scientists are conducting fundamental experiments upon which the therapeutic advances of tomorrow will be based. Their seminal work seeks to understand the retina in the context of the human neural system and other body systems, and to identify the life processes that support this essential tissue in our eyes that makes our sight possible. RRF funded researchers study what causes the retina to work properly and what causes it to functionally fail or be disrupted, which results in disease. Their findings provide knowledge and foundational data that leads to better ways to predict, prevent, diagnose and treat disease. The process toward significant therapeutic advances takes time, resources, and commitment.

Researchers commonly refer to the fruit fly by its scientific name, "Drosophila."

Scientific breakthroughs often come from unexpected and surprising areas, and for vision research, organisms distinct from humans often provide key insights or novel properties that lead to advances. Currently, RRF is funding pilot studies examining the vision systems of organisms as varied as the fruit fly, zebra fish, salamanders and mammals, primarily rodents such as mice to learn more about these model organism visual systems and thereby, expand the understanding of the human retina.

> *"If I have seen further, it is by standing on the shoulders of giants."*
>
> Sir Isaac Newton



Each year, RRF funds projects across a wide range of novel topics that aim to understand retinal diseases from many viewpoints. Supporting a broad and diverse scientific portfolio increases the probability of breakthroughs and builds the strongest foundation upon which discoveries can emerge. The resulting, basic scientific discoveries are shared with the broader scientific community by publication in peer-reviewed journals and during rigorous forums for discussion, though presentations and poster sessions at scientific meetings. RRF-funded scientists have published nearly 1,000 scientific papers contributing to the scientific literature. Collectively over decades, researchers' contributions have constructed an expanding scientific base of knowledge that ultimately results in the therapeutic advances like those benefiting patients today.

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RRF is a public charity and our efforts to cure retinal disease are enhanced by support from our community. RRF accepts online donations at retinaresearchfnd.org. Use your phone's camera (Android or iPhone with iOS 11 or later) or your iPad, to scan the QR code displayed and open the secure link. Of course, you can always mail your donation to the RRF office.

For more information on ways to give, call: 713-797-1925. Thank you for helping RRF fund innovative research to discover cures for the retinal diseases that damage and destroy vision!

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