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[http://www.natalieswish.org/Grants-Awarded](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgikF_IQ9eoVeWrePseqVsF-ioukgS2f2uE_8Ib_qRkWpg23wuZxXP0Jcm_v7gneR32xFTwcwYBeNDEV43onYavyMf1BIrkfOZthqnN2OyTjzxtrHsABhrNbBw9l215yU9-VNqQBLiMXK7ZRn7t5QUqUjDkFni7YDuGtOcU7w9_-smg6tWksJmGfQT_v8FBV2glVkFmqRz2y8NCbf8ibeOZUrvLOHBBHEus4f5b-Av3iXhwzVokjRTsKg1ColWKSTiXhg3q1rsdLpA_nP6CzH-i) |      |  | | --- | | **CRF Announces the 2013 Fall Call for Research and Fellowship Proposals** - Currently $1 million is available for cystinosis research and fellowship grants.  The application deadline is Friday, October 25, 2013.  Successful applicants will be notified by the end of January 2014.  To apply visit [http://www.natalieswish.org/For-Researchers](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgNYRh3Hw1n1oCc1XRCp6s_tGGpq0YhQsJUZKuGe3eEc0YMd5OS6zNfUEcUis3nZsle5C5TQNg6ziorhRJHwFLo9HD-39yMZ8xyuCjB5HVQYV9EGKbkjLuH7Cs7XhIbuln-hiJRiLfH-mQAVK5GyH0TYIgp7kbhkXxXFwxMO4i0xUvcJiL2PYKqDsQaSKqeMAQ8P7t5ZHD5n1y3iouTaAvHP_l1tJge5_8BdzDqk74Kv_r1WhAoVoV_1XOy-Pa4sGAQZrHElEGeGlMr8Rmhxvkg) |      |  |  | | --- | --- | | https://imgssl.constantcontact.com/letters/images/1101116784221/SpacerImage.gif | **RESEARCH UPDATES** |      |  | | --- | | [Molecular Study of a Cystinosin Homologue and its Impact on Cystinosis and Cysteamine Therapy](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgG3Sq9MXgYgv5muEhmzQ9S9EO2XARL3wpyShpw3wXm9WN4SQUceFuQeMSlnjNn-K09WdrlsC90aaJ3aRLzJuYPjpFlayrldhqPMFy0expRcvAYVSj3MpNvcj2vkasi_UDP5BpejcNP7a4bq8XFaSljrl9JS-B5qf-ftjt1j7bTc5qI-e9f5Lt9iPC7UR11A4erBcPzRtN26VaM9dWHGp-l4mqa8aDiIWfcaO73VgOCyzph7e-8N7QDgyYn8Pw9BMmqOYC4ozihcenmR47yzzofsINbQHDxu9PMWqr1jCBM57SP7XTBNhUB)  Two-Year Study - Funded September 2012  **Bruno Gasnier, PhD, Principal Investigator** **Bruno André, PhD, Co-Principal Investigator** Université Paris Descartes, Paris, France |      |  |  | | --- | --- | | https://imgssl.constantcontact.com/letters/images/1101116784221/SpacerImage.gif | **PUBLISHED STUDIES** |      |  | | --- | | [Is Genetic Rescue of Cystinosis an Achievable Treatment Goal?](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltjmKEGFPqYcFcNptNTLd0aET0dYbHDR5qAv4gWzVpfMYgbT2cuMTE-72N8-4rm2Huw4oQp8WMAlPHM65uNfMQYch5S4Xogl7pZhptyoVlMCCl9ZfYy5HrVibsQ9U6jaFLnO8IqHcs8kph_n3t8Ah_4O2wGkLDvmfh4pQiYmJI2pH5A6DRJbSfudBZbtvdLqk_D2tlYefIjik-BZk6_LylFcRwkuyM6xONh-rV74RV4Qie0rzXjpN-q2wMDeOeE2xp6UnN5dpR31kuvS4xAQ-tGh3kJt9a5Mlg0=)- Published July 16, 2013, Nephrology Dialysis Transplantation: Oxford University Journals by Dr. Stéphanie Cherqui, University of California, San Diego, La Jolla, California. | | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  | | --- | | **In This Issue** | | |  | | --- | | [RESEARCH UPDATES](#LETTER.BLOCK34) | | [PUBLISHED STUDIES](#LETTER.BLOCK48) | | [CRF FORE A CURE GOLF TOURNAMENT](#LETTER.BLOCK50) | | [JOIN CCIR TODAY AND BE PART OF THE CURE](#LETTER.BLOCK36) | | [CYSTINOSIS FAMILIES UNITED FOR A CURE](#LETTER.BLOCK26) | |  |  | | --- | | http://img.constantcontact.com/letters/images/1101116784221/S.gif |      |  | | --- | | **Quick Links** |  |  | | --- | | [About Cystinosis](http://r20.rs6.net/tn.jsp?e=001ztVLrznblti7j11mKY_Kf5de6e9pZiAflfR9AnCMCoZxmzVd_-cUDLR-jXMKa11atVcl_BhVp4IIttSTFYlQmr6vCRnfeNFBg93JRZ5iXdiB_9UO_2zLOJEnkwPhrw63MaQnuOfgFmEHjTQKio6R6iOsJ0vgUupJtYuyWNhfE1mvVB7b2o7Dcwzg-KV2FzGIBrC7lCRxSauxQ4RK4qTlw1MRFZewOEbEX_FwKSUIND8KJGV1VrOwycbDhQicHtxwqzr9a13R6mDoU5j_uk0Cut2ltS5pFDdsnMNGlr6TQFA=) | | [About CRF](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltjIkA3kKfhSu4fGRbD2417jCkytwbX-RpEDiqRvtyqBNilC614Eo5kkLEonEg1d4OuYY3Xi4CBs6YRXi5syy0roEmN6xOOCXcY36PzmeGXJyAt-VV-JtG-LgryM1g-_VQyLCGRsl-vBerx8GMOUYeWWAtLx_PxwEZLoC33ZBo6E71mlKXHSDvbCqxebNlR0vQ8o2R2HjH4mIIF5gMoUsfvaBJdkr6hDkdlsEid2IE1A7q2Yh6CJyMEWPReRBa2owgTbTl3I3KgguufUCz6ep1EV) | | [Cystinosis Families](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgfxQEVTfUGioaBl1XlwdKneVdQeILCrxn_hCmB3yfj4yVMZjkRTIqNZIuAu3agEDZsP-_RuqkUljIyirXxnNY_TONaChV_bAtvWUDj1YTRJH2PBGkpwq32DVR9H4_DBVAov141FWBK_yDBJXVB3OSNlfC5NoYJkgcd722kIyDf7R8aanCCYNRk_MxOEH4IJiNnnRSi2Ou7d5M2wPRGbQ2LL9eEGerOnYjiPjEBvR66PLfxzA-_NdsBB_8rKH3t_IS5NsfGUHheLj4R7PjZVRTlcIqDBGhI8yY=) | | [How to Help](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthEfc3JEwETeaR02Mjz3PD0wdbRwqSCpYHJn4PG9FuSwQGucdONN3mA4MsfIYxGY1T2pn2x8YHaVpakROlD_l4iOnhgdW9vzMqUjZKs7RR2jhgpSBjhD1sqW4FbsS6mF0RX12DUdgecj1jeWqhk0Rh3NmPmAg8_N-HCaPAtSKpIDsMWB1JmvUUf1_Oe8vJa7LMkznry3oXw8DUlf8Yjo29xesqDLI7fqEhkK1h1Hf27Kskx5MzxpDpTXcm7cv0D0OfkrneG1RU-oT3PbqjLXk3J) | | [Find a Doctor](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltjS7Yzdj7HIX9rrfP6Kzvx8ksGNAO-M93cRmiCKekH9--7NNsKdcl9xz9O1E-7SI8vGNyTdjS8czBCIZAKfu6YGawOL4gXVBdmD4156bhRcDAUzB19gsZaQLNLmICOUY_X7wPlrszcB3kddq2-XE6QO6MoD_ehaAvA8V7rJNacnBad0f1eosJzXy-8YvEoo6nmpq2InyxcVtYh3CdcUoZmNtG0zG3_oFUK_AL1Gx84ACSFvA8Oq_Xav_ynO4eVUvnq2pj_lugZ37i8i_55uSkDdbwxxgx7SZ3objN7U_DnsyQ==) | | [Events & News](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthRYFtG40WoSmAULkWCPtRZxuz8BiCKwXwT7xZop3GAaaeDdyFdle6iKI3TsIO07h5MuBLPcS4ug_ERSaljD51B6ZCkpbvfjrvhCKagvd0qu78lIyFZdHXeCwVkGQhV9LH-XrGn8QQXOlCa6ivk9wOk3hm1PccKmVan7zKLc1mbj773UZfQrkoF0Ft9UweRTM-cfA8Hi65QQXMW2vf3BRHc35qb67emzmNCfqY55uCe_viqc2V-nzpQdBdUDlO_ozviHRjzAcJPT8zWpcOHwHHc) | | [Research](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltg6LxuC_DDyRa8e3vJZtSfgj5GrnxGRLNfTKde5f84iOC5Op0c_Nc3rJ5Qux427gbKbGvuAaNCSsONisxLsic0tU7uf34c7VuFyT5b3ZBa80qmvmbxB0cR3r68P6n4WG0T-zXHiwiC7A-nz8O_B5Pjj8WziJe8QEwuqjhwaXEuxl4-4MAru3h0bVRQcPf6rrm6vZhyM5xo_M0mbEZ88GU4Ba09sPDq0DMI6PzGFhtG2kUcVKw22LNkiFxqs_450s8sZUSzd9sa3qM7-Z3sr3M5R) | | [Contact Us](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltjxM64NExg5OPxec2zdvBi8VEz33cV4y2CnidpM8_uyG6xtLfjv5yBXikhcP-WJd0oLDNgCg6jpyJLciu--8GKKG6F6UNe0_zFXHJXIO1VCihGn5RIDMBSEQAc6R2HD9RxUaHkdy2MTZ6tU8SnqaiEm51MeTDvBrUZ0uWBrLzyB8x--dgTnXZ_7VfseKPEr3_HHJFQCKmNnFGfcQH8CLnv6LyJmOKhGUCRWkfIbQeJ-Hk2zjfark3cROi-0R-IJT35mpdAQg9iZHtBfqOePU6F1) | | [**Donate Online**](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltijBoqYqMdEOv-mPDXByTmsivhIRquMkNF5ApeE2vJJ4TLyLYSt22DOmuS8qiPmOOwyZ_F0-RFIB33PmNDLNWs75djXvyBoUmr8OktLJMTIlYd_QyT-9ubsUC1hcw1bIB1ORO_MYO0HKXLONr4K3aLaD1psucdoHqv61tYqcaCpO6bLT0DaiwA_G1bY7HBVIAEk9io-kSYfz3hnpIfRoonY6PF-5jU3Cp2EYZq8icIH33PZ9uFm0fFJIpYKUrcmCfyAfyyt_-zckq9fEBNxRUFeo3IT6CwDmhc=) |  |  | | --- | | http://img.constantcontact.com/letters/images/1101116784221/S.gif |  |  | | --- | | http://img.constantcontact.com/letters/images/1101116784221/S.gif | |  |  | | --- | | http://img.constantcontact.com/letters/images/1101116784221/S.gif | |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  | | --- | --- | | https://imgssl.constantcontact.com/letters/images/1101116784221/SpacerImage.gif | **CRF FORE A CURE GOLF TOURNAMENT - Monday, October 28, 2013** |      |  |  | | --- | --- | | We are grateful to our community business leaders for their dedication and support to help find a cure for cystinosis.  The tournament is sold-out of golf sponsorships but underwriting opportunities are still available and tickets can be purchased to attend the evening's festivities which include the cocktail reception, silent auction, awards dinner and special live auction.   [Visit the website for details!](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthKaNiQKQ_1HfCtGbBC-Gf5vmjnHHxvQSrFzdTamRPkftQuxwG1UeHPJchGMHKtQG5hyBsS7wFqyXAjU3HAf3m22PO871TQRa1W_n0jbM3wP2dRaXCeDESG1MawzVeRhuPopOthePqYP5YeYmTEx7aeRauWst2enZEc38I-oL9IxV6wjoeanmo3JmT_ApmUUTH30mOb9gQnJwKth06Qt_ufOu6j7W6KQvn_ungDOqyOH46WUiHieJ32tL96padn55KDWtFuueUKRmxlxh1iwgPra5mLJXu5e_web5cEfNfVfg==) |  |      |  |  | | --- | --- | | https://imgssl.constantcontact.com/letters/images/1101116784221/SpacerImage.gif | **JOIN CCIR TODAY AND BE PART OF THE CURE** |      |  |  | | --- | --- | | CCIR is happy to announce its 2013 gift card campaign.  For a limited time only, CCIR will provide a $10 gift card or a $10 donation to a cystinosis charity (you may choose from organizations that are CCIR advocates) to those who create a new CCIR Account.  People who are already registered and have not updated their profile for more than one year are also eligible to receive the incentive if they bring their CCIR profile up to date.  Visit [www.cystinosisregistry.org](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltjUhTvHlyM1QCRLPXdNeHWQLT6Hyh61WxhuFC295GV17fQk7q7PC4Y-XAzZ8Hj_pDiSmpi90u18Q3HJfzPb9eYAwiNJtKxB2HPLgErzEWegI5eB2-MpvC_ey_KQfGUQlh7iPIXmDm1poeHXmtTeVOyFQt5dsEfR7p3tAaweX-DShfGa4lRibm0Pn9hEGssXknxb7Zh5Pghp3XlDsEeSJA4DmoSRpzQFcEAHQEb7RqeLsNazCPTgohZ9e2YL2PtgwLT0o8WFEmA-VA==) for details. |  | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  | | --- | --- | | https://imgssl.constantcontact.com/letters/images/1101116784221/SpacerImage.gif | **CYSTINOSIS FAMILIES UNITED FOR A CURE** |      |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | **Sunday, September 22, 2013**  Port Elgin, Ontario, Canada - The **First Annual Swing, Shoot & Live Golf Classic** will be held at the Saugeen Golf Club in honor of Olivia Little and the Saugeen Shores Winterhawks.  The festivities include a day of golf, BBQ lunch, dinner and silent auction.  To participate contact Erin Little 519-832-5188 or Gord Lamont 519-832-2187.  Register at [www.saugeengolf.com](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgaRJPkSKLb2xur6SJZdTVBC5ANM2vATlmgFAwS3trBKOWp_7GTXpIzEbpt7hP6FD28okjpHSUPmR3ofKLVDDIfcPLV5u6EZK4AnrzjOywzeIEVzvGJy9UjUk9skJppnWe1X2gbAYQDzJikAG4zh5O4h0g4d89RnxwNqRAJtzHLoOg2D0_q5TovUwurlbg4WPPduiPiJTIOHgbFhsBeJEfvtxZvkYK_ne74Rj4jOGhzfVgMbYgJFdDzV6MGLIoTnCo=) |  | |      |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | **Tuesday, October 1 - Thursday, October 10, 2013**  **Joshua's Journey of Hope On-Line Auction** - The JJOH Foundation is hosting their third annual on-line auction fundraiser in honor of Joshua Clarke.  Last year items worth more than $35,000 were sold for less than 30% of the values.  What a deal!  Visit the bidding site and take advantage of a wide variety of activities and discounts and shop early for the holidays.  Log on at: [www.biddingforgood.com/joshuasjourney](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthh3fcecdLwCA3KfldRN4GmXfmPH2P-pYf9q3E80dqpBum3N45pdntBoeADuEvDa9ZUIBc2E9RIrUToLtHgm_SnD_VAlEg91nBcrIJjVJqA-uwc-y7-pJTHV3gFgg_47Nvx_uCZtRok6pRF6fLCn3TXrGQ8evN5Odumbk03KK6heRKs2qyqY4Iyf9Dt7oqrUxH_N9yJz-6H6n8iiUfVOb8GBsBuilzouuN-3n5PHdYGgh4OY2vt4c9S7Oj5LHIOOUssYiG0VIy_QwTrdiWq-N-M) |  | |      |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | **Saturday, November 2, 2013** The **Third Annual Lots of Love for Landon Halloween Party** hosted by Lauren and Jimmy Hartz, will be held at the Home Economics Building in South Park, Pennsylvania from 5:00 p.m. - 9:00 p.m.  The festivities include dinner, auction, door prizes, costume contest and entertainment.  For tickets or to make a donation visit [http://www.cystinosisresearch.org/Donate-for-Landon](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthmnNgJd_w4XXFLcfq6b3Oz0FUkgP9VAqTkkNUrfRKPwVOQ2ddd3bMuhhnwDspB7IP3OBtM8HYafle5RmH_kT-Cu_hZji5OoznEdVcx27xbepMzo3NiRzQE_IIkkVbUctbC-JpFOepi-JxbMmpiRhSjhWCE_uC2F0pSaJRfW7dTpQz-9DHgR9-WNwzoczXhZkx-OqEKN4hJMc2-OyJaFewKoxi0cDsel-izT5rhOSgksKyt3B9cyCQE9AeqJnoT1qJsfv-N3HCrLrI1yDUYaThGCAaogt0qlSg=) |  | |      |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | **Saturday, November 9, 2013**  Barstow/Stoddard Valley - The **Second Annual Ride for a Cure**, in honor of Bailey Dedio, will be held from 9:00 a.m. - 5:00 p.m. in the [off-highway vehicle area](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthtkqekhXTEvKhtZJQ0apXJpaTNlzW5GokH7-n1r59LE9RuHoGq3V76lOgPU0okqOBLdkH3WSOwGMLWD_as0HpNWLwqV0NJR-ru0-7yn-oYCMyr2BE32YtWJoJMoRHz_r8ntFLsvxkKq3N--88WWuaDzT_dFHrksIvjvyGojcdBYPiQDX4b1Pngx507RxJh_VkTrbHQkcr6tBbXDcfUMhequYT-Cv5KafLdyd0NgTYlD07C4bfbLQI5-p82DndGqS9RX1CCf0KeuUPd7MLHWuR2RVz02tw3f6xoygDi-bNHNg==) of the Mojave Desert in Southern California.  Join in the fun-filled day of racing, entertainment, food and activities including a silent auction and opportunity drawings. Tickets for the ride are $40 to purchase or donate visit [www.cystinosisresearch.org/Donate-for-Bailey](http://r20.rs6.net/tn.jsp?e=001ztVLrznblthZwsdlg8alXXO_R18wOebvvPDsuMg-mtfmQnBwVik8cam3ToDdAVxTBWMeI-DY9xygILbzLhZCwSoB7Q-9QcxzfyERbQt6klCFVZS6emrdDz-nfXUpx-zqN1BPJv1ok2pjN2NiAhOybz9wHX0i9Z0daTCXVvHAhkOjLWsZOEk11oJpJaYMIN04EnSez1tCz-OodX70cof6pTxFkwYHTV3h4fWxLx957bjju2UODxOcQTVqzUAxixKLNlM4MadzoEpGvNZCVJBdgkF1U74yZJbVJ9KhyapqH5s=) |  | |  |  | | --- | | http://img.constantcontact.com/letters/images/1101116784221/S.gif |  |  |  |  | | --- | --- | --- | | http://ih.constantcontact.com/fs123/1111749637986/img/5.jpg **949-223-7610** [cystinosisresearch.org](http://r20.rs6.net/tn.jsp?e=001ztVLrznblth81-Ta5f4wpd7ZeXIXWMH9LzWbebbP6Tf211SVEgBUUCmOe1Y7bPz4Nvj7AzhLlRhiZckr0rqvNvmyu45D3QBDWEmC-obLkV6vyQhtF_2BBXS7kYSBF-SC-k5Gq8UVmkYG9InRhhw46Dz06yfLr9_h6y5crMLN5F7yuusT8kzg1kv2nerdY09HgSE-ym4f4QjnuFj88tpy1bq8fxwrpLfLLaTTmGhRRQIh0VRGAwpVJ04WNTsNcyL7KBCAsEFak7eW2oh9sQ3MxA==) | **The mission of the Cystinosis Research Foundation is to support bench and clinical research that is focused on developing better treatments and ultimately a cure for cystinosis.**  Cystinosis is an "orphan" disease affecting approximately 500 people, mostly children, in the U.S. and 2,000 worldwide.   Cystinosis is a metabolic disease that slowly and eventually destroys the organs in the body including the kidneys, liver, eyes, muscles and the brain. Although medication is available to control some of the symptoms, cystinosis remains incurable. | [Like us on Facebook](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgL_Tvrf13eeSFxmvZzdcSzH9dJk29OMKE7S47BTqAYnRgovbm-bAu28lPhvSQ93WgnOQamZXZ3BRXaxigUpMSdTGrk8eyngFwQaf4lChe_qES2PfoyMnrXgYK4VNxZjt4gu2j-JizWUQ==)  [Follow us on Twitter](http://r20.rs6.net/tn.jsp?e=001ztVLrznbltgXTCncdIvZ76YEoZuC_oI8P5C_OxTSUTcsr8_RYOt9mftqPPXdoIBfDKHl1s3R1AVsHxDmC5n9W6g2pp1fB-I5kzTytNshpOc4xyEGJaysrz2KG0683URi)  [View our videos on YouTube](http://r20.rs6.net/tn.jsp?e=001ztVLrznblti4yYW0TrX_sb6dg2DCL89jygXNOdK3HhlHiXn_3htb2rdfoRxypk2pgbz7sd_Lh2A50OKehCTvpEf37Wr_cIcZ4fLpVkn9WGnRwClaWrQ399wUE26WSoaCur25G48wP08=) | | | |